

**RELATIONSHIP BETWEEN EXPERIENCE OF
STIGMATISATION AND COPING STYLES: A
COMPARISON OF INDIVIDUALS WITH ECZEMA AND
PSORIASIS.**

BY

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DECLARATION

“I certify that this is a true and accurate account of the work carried out.

This thesis has been composed by myself and the work herein is my own”.

Signed ...

Lucy Victoria Kelman

ABSTRACT

It has been recognised for a number of years that patients with chronic skin disease experience a range of psychosocial difficulties. These include feelings of being stigmatised and the stresses of coping with a disease with an unpredictable course. To date, there have been few studies that examine the effects of stigmatisation caused by chronic skin disease. Researchers have suggested the need for a better understanding of how patients deal with the psychological aspects of skin diseases, as well as an understanding of the coping mechanisms used by individuals who feel stigmatised by their skin condition. Currently, no study makes comparisons between psychological difficulties in eczema and psoriasis patients. The current study examines the relationship between the stresses of having a chronic skin condition, feelings of stigmatisation and coping strategies adopted by patients with eczema and psoriasis. The participants were all dermatology patients, both inpatients and outpatients, who completed three measures exploring coping strategies, stigma experience and psychosocial impairment. Some participants attended for follow-up interview, providing a more personalised account of problems faced by eczema and psoriasis sufferers. It was hypothesised that participants who reported greater experience of stigma would relate a greater degree of psychosocial distress and show similar patterns in their coping strategies. These results are discussed with reference to current literature and suggestions made for future studies.

CHAPTER 1 – INTRODUCTION

1.0 GENERAL INTRODUCTION

Skin conditions affect a large percentage of the population. It has been estimated that between 10 and 12 per cent of all General Practitioner consultations are in relation to skin disorders (Hunter, Savin & Dahl, 1989). The research literature suggests that skin is crucial to our sense of self and how we promote ourselves to the world. Consequently, skin disease can influence an individual's psychological well being. The majority of the research examining psychological factors in dermatology has focused on stress as a cause and/or consequence of skin disease. Recent studies have become more interested in the impact of skin disease on quality of life and to a lesser extent on the experience of being stigmatised.

In the introduction to this study, the opportunity will be taken to explore general issues relating to the skin and specific factors regarding eczema and psoriasis. The relationship between these conditions with experience of stigma, coping strategies and quality of life will also be examined. In addition, current literature relating to psychological intervention in skin disease will be discussed.

1.1. PSYCHOLOGY AND THE SKIN

1.1.1 Emotional Factors

Skin is the largest organ in the body weighing approximately four kilograms and covering an area of around two square metres and acts as the interface between humans and their environment (Forsdyke and Watts, 1994). As the organ of touch, temperature and pain sensation, and as an erogenous zone, the skin has great psychological importance (Savin and Cotterill, 1992). As James (1995) notes, it is evident that psychological factors are associated with changes in the skin: emotional expression involves both sensory and visible changes in the skin. Consequently, as the skin reacts directly upon emotional stimuli, dermatological conditions frequently involve a somatic dimension (Van Moffaert, 1992) and those with skin disorders carry with them disproportionately heavy psychological punishment. As a means of communication, the skin can be very powerful. Gupta and Voorhees (1990) suggest that an individual's skin can communicate emotional distress, and underlying the dermatological problem, there may exist a full range of personal and family problems. In terms of management of dermatological conditions, it has been estimated that for at least one third of dermatology patients, emotional factors precipitate and/or maintain skin conditions (Koo & Pham, 1992). Although the prevalence of psychological disorders in dermatology is unknown, Hughes, Barraclough, Hamblin and White (1983) document that dermatology in-patients are known to have a higher prevalence of psychiatric disorders than general medical in-patients, and that dermatology out-patients have a higher prevalence than the general population.

1.1.2 Body Image

It is well recognised that our skin is integral in the development of body image, promoting a sense of well being and is an important contributor to social reputation (Kreugar, 1989; Jobling, 1992). In many different cultures those with a skin condition may experience a sense of shame and guilt and anticipate the threat of social rejection (Jobling, 1992). In reference to psoriasis, Ginsburg (1996) suggests that one of the most distressing aspects of the disease is how it attacks the sense of self and an individual's ability to accept themselves as a worthwhile human being. She goes on to discuss that if the skin is seen as abnormal and defective to the outsider then it seems to apply that the human being inside the skin is also defective and abnormal. Given the emphasis in society today on health and external beauty, skin disease can make a person stand out while other illnesses are not as visible. Koblenzer (1997) has reviewed this further with particular reference to women. She thinks that the emphasis on external perfection and the power of the media to promote perfection creates huge difficulties for adolescent females as they adjust to their body image. This is immeasurably greater for the girl without perfect skin, hair or figure. Gupta, Kirkby, Schork, Gorr, Ellis and Voorhees (1989) note that 58 per cent of psoriasis patients develop the condition before age thirty and suggest that a significant number face cosmetic disfigurement at a stage when they may be most self-conscious about their appearance. Others report anecdotal evidence that the psychological impact of having a skin condition is more evident when the disorder occurs during this developmentally critical period. This is a stage when individuals are seeking to establish and maintain a good reputation and position in social, sexual and economic competition (Gupta, Gupta and Haberman, 1987 and

Jobling, 1992). As a consequence of this cosmetic disfigurement and social stigma, a vicious circle is created; the individual may develop disease-related stress reaction that in turn exacerbates the skin condition adversely affecting the course of the disease.

1.1.3 Psychological Problems Associated with Skin

The scope for psychological difficulties, when there is some degree of skin disease or disfigurement, is great. For centuries, the prevailing view in medicine has been that psychological factors have been important as the cause of skin disease. It is only during the past fifty years that the opposite view, that skin disease cause psychological problems and disability, has been accepted (Finlay and Ryan, 1996). Despite this, much of the early literature was concerned with the role of personality traits, which were thought to predispose individuals to skin complaints. James (1995) suggests that many of these early studies have created misconceptions among dermatologists about the role of psychological factors in skin disease and consequently many introductory textbooks lend little credence to the area of psychodermatology.

As the skin is exposed to view, any skin disease readily elicits reactions from the patients' environment. Furthermore, the easy accessibility of the skin allows individuals to interact directly with their skin lesions, so that behavioural factors such as touching, scratching, exaggeration or neglect of the necessary skin care are likely to complicate or create further lesions (Van Moffaert, 1992). As skin conditions are often visible, this carries the connotation of contagion or a lack of hygiene and may cause the individual to feel ostracised. The resulting self-depreciative feelings may lead to social fear and

shame and further psychological distress. It is important to remember that the exact impact of a skin condition is dependent on individual experiences. Although many people will react differently to the same condition, there is some evidence that certain skin complaints may result in people experiencing a common cluster of problems (James, 1995).

Following interviews with 100 individuals about the impact a skin condition had on their lives, Jowett and Ryan (1985) concluded that a cosmetically disfiguring condition can result in social disapproval and increased self-consciousness impinging on employment, social and personal relationships. In skin conditions such as eczema and psoriasis, both non-specific emotional stress factors and specific life events can trigger a relapse, affect the onset and duration of symptoms, and affect patient compliance (Van Moffaert, 1992). Cotterill and Cuncliffe (1997) suggest that males and females with facial disfigurement may be a high-risk group for suicide and review a number of case studies of suicides in dermatology patients.

Symptoms found in dermatological conditions are frequently associated with psychological problems. Pruritus (itching) is defined as a sensation that provokes the desire to scratch. This is the most common symptom of dermatological disease. In psoriasis, pruritus may be a symptom in over 70 per cent of cases (Gupta and Voorhees, 1990). Depression is frequently reported to be prevalent in individuals reporting pruritus. A study by Sheehan-Dare, Henderson and Cotterill (1990) reported depressive symptomatology rates of 32.4 per cent in generalised pruritus sufferers compared to 13.2

per cent of controls. The authors concluded that it was difficult to determine whether pruritus is a symptom of depression or whether the higher incidence merely reflected a reaction to such a persistent and distressing symptom. Other researchers have suggested that a depressed clinical state may reduce the threshold for pruritus. In a study of self rating scores of pruritus, Gupta, Gupta, Schork and Ellis, (1994), found individuals with either psoriasis, eczema or urticaria showed a positive correlation between self rating indices of pruritus and scores on the Carroll Rating Scale for Depression. Other studies have examined the link between pruritus in atopic eczema and mental stress (Jordan and Whitlock, 1974). This is a potential area for further research to examining the role of psychoimmunological factors. Authors such as Folks and Kinney (1992) have noted that other syndromes, known to be similarly influenced by psychophysiological factors, such as migraine and irritable bowel syndrome, are frequently reported to co-exist in patients with dermatoses. They propose revision of the Diagnostic and Statistical Manual category of psychological factors affecting physical conditions, in order to improve the quality and depth of future investigations.

1.1.4 Psychological Classification of Skin Disease

Several authors have suggested classification of psychodermatological disease (Koblenzer, 1988; 1997) and most have defined three broad categories. The first is related to psychiatric disorders that manifest in the skin such as dermatitis artefacta, parasitosis, body dysmorphic disorder and obsessional habits and concerns about the skin. The second category relates to conditions with a psychogenic factor such as urticaria, pruritus, flushing reactions and alopecia areata. The final category relates to

skin conditions which are probably dependent on genetic or environmental factors but whose course is often significantly affected by psychological factors. This category includes conditions such as psoriasis, atopic dermatitis, acne vulgaris and potentially the whole spectrum of clinical dermatological conditions.

1.1.5. Summary

Looking at the available literature it is clear that skin plays a crucial role in psychological development and functioning. When an individual is afflicted with a skin condition, the potential for psychological distress appears great. It is Koblenzer's (1988, 1997) final category of skin disease which is examined in this study, in particular eczema and psoriasis. Both these conditions are described with reference to psychological functioning in the following sections.

1.2 PSORIASIS

1.2.1 What is Psoriasis?

Until it was identified as a distinct disease in 1841, psoriasis was described as a variant of leprosy and regarded as contagious. Psoriasis has an unpredictable course and can first manifest at any age with a varying duration from a few weeks to a whole lifetime. The disease is characterised by red raised lesions covered with silvery scales (Taylor and Buckwalter, 1988). These psoriatic lesions are produced due to acceleration of mitosis

which leads to an accumulation of cells at the skins surface producing a scaly appearance. Onset of the disease may show a bimodal distribution, peaking at 21 years in males and 16 years in females, and then again for males at 57 years and 60 years in females (Klaber, 1992). There are no sex differences in the occurrence of psoriasis. Early onset of the disease and a positive family history predict a poorer prognosis (de Jong, 1997). Little is known about why psoriasis develops, but some triggering factors have been identified such as infections, in particular streptococcal throat infections, endocrine factors, hypocalcemia, cold and damp climate, various drugs and psychogenic stress. In a large study by Park and Youn (1998), examining factors that influenced psoriasis, results indicated that summer; sunlight and pregnancy were favourable factors while effects of winter and stress produced adverse responses in the majority of subjects. Psoriasis can manifest in several different forms and can appear almost anywhere on the body. In its most acute state, psoriasis can be life threatening. Psoriasis sufferers may also develop photosensitivity and psoriatic arthropathy, a form of arthritis (Klaber, 1992). Although modern medicine and techniques offer symptom management for the sufferer, there is no specific cure for the disorder.

1.2.2 Medical Treatment of Psoriasis

The relapsing nature and wide range of clinical manifestations of psoriasis leads to many therapeutic problems. Treatment regimes often need to be tailor made for each patient with allowances made for the individuals psychological and physical reactions to their skin condition (Judge and Griffiths, 1992). The most common treatments often involve the use of greasy, pungent ointments such as coal tar. Jobling (1992) argues that the

patient is soiled by the existence of the disease and the nature of the treatment reinforces and amplifies the disabling nature of the skin condition. More recent hospital treatments such as light therapy and oral medication have many side effects. Light therapy promised much when it was introduced, but the negative side effects, as well as the benefits, may affect psychological well being. The pronounced tan, which is a side effect of the treatment, can lead to unwanted questioning and may be viewed by others as vain (Jobling, 1992). This may be particularly marked when patients receive treatment in the winter months in the light of public health warnings about avoiding the risks of skin cancer. Jobling (1992) also comments on the unrealistic expectation of many individuals that light therapy is a cure for psoriasis. This undoubtedly leads to disappointment and potentially heightens the likelihood of anxiety and depression.

1.2.3 Life Stress in the Onset and Exacerbation of Psoriasis

Psoriasis is not only influenced by stress factors but can also serve as a stressor in itself and can negatively influence the well being of the patient (Judge and Griffiths, 1992). There has been a vast amount of research examining the role of stress in the onset and exacerbation of psoriasis. Al'Abadie, Kent and Gawkrödger (1994), in a review of the literature, estimated that the proportion of psoriatic patients whose disease is affected by stress varies between 40 and 80 per cent. These figures are dependent on how stress is defined, whether acute or chronic, and how it is measured, generally by self-report or on standardised checklists. The study by Al' Abadie *et al.* (1994) asked a group of dermatology patients to rate if their skin condition first developed after an important

stressful event and how soon after this event it first manifested. Although the sample size was small, they concluded that stress was a more significant factor in the onset and progression of psoriasis in comparison with other skin diseases. Other studies, such as Invernizzi, Gala, Bovio, Conte, Manca, Polenghi and Russo (1988), have looked at the role of stress in the onset of psoriasis by comparing the number of psoriasis patients who experienced a stressful life event in the past year, against a group of controls. Over 75 per cent of the psoriasis patients reported a significant life event compared to 23 per cent of the controls. For a majority of the psoriasis patients, symptoms appeared within one month of the event. General research examining the role of stress in psoriasis has clustered in three broad categories (Ginsburg, 1995). Initial research tended to be mainly based on anecdotal evidence, which was followed by large-scale epidemiological questionnaires. After this, research based on life event methodology emerged and more recently, work has concentrated on the combination of life event with standardised questionnaires. Ginsburg (1995) has suggested that the life event may not be the trigger per se, but if a stressful life event takes time and energy, an individual may not be able to maintain their treatment regime and thus trigger a flare-up in their skin condition. As psoriasis patients frequently report improvements in their skin during summer months, the particular time of year and exposure to sunlight may be a confounding factor, if patients are included in a study at different times. Types of life events identified in these studies also vary considerably. What one individual views as a single major event may be a more frequent minor occurrence for others. Due to the problems in defining stress and the methodological difficulties in these studies, it is difficult to draw any conclusion, especially when no longitudinal studies have been conducted (Ginsburg, 1995). Flaws

in methodology are a major criticism of the extensive literature examining stress and psoriasis. Park and Youn (1998) suggest the main criticisms of the current literature is that the studies are subjective, do not exclude observer bias and that they are largely uncontrolled.

Gupta *et al.* (1989) looked at individual differences in responses to stressful situations for psoriasis patients. One hundred and twenty-seven consecutive outpatients were asked to self-rate stressful situations frequently making their psoriasis worse. From this, subjects were defined as high or low stress reactors. On completion of an extensive psychometric battery, results indicated that high stress reactors tended to be younger than the low stress reactors. There was, however, no significant difference between the mean duration of psoriasis for either group. High stress reactors reported experiencing more disease-related stress than the low stress reactors. It was also noted that the high stress reactors had greater psoriasis severity on their scalp, face, neck, forearms, hands and genital regions. Gupta *et al.* (1989) label these areas as emotionally charged. Interestingly, there was no significant difference between overall severity of psoriasis between the high and low stress reactors. This is in contrast to the study by Park and Youn (1998) which found those with more extensive psoriasis, not related to any particular anatomical area, regarded their psoriasis to be more stress related. In conclusion, Gupta *et al.* (1989) suggest that having psoriasis in emotive areas increases the risk of an individual experiencing social stigma and thus increases the vulnerability to the stress associated with this. Consequently, minor long-term stresses associated with having psoriasis may have a greater impact on the disease than acute and generally

short-lived major life events. Gupta *et al.* (1989) suggest this may explain the varying and often conflicting research examining the relationship between stress and psoriasis.

1.2.4 Beliefs about Psoriasis and the Role of Stress.

With such a reliance on self-report measures, it is important to consider the individuals prior beliefs about the cause of the disease and to acknowledge the considerable variation in how individuals react to stressful experiences. Fortune, Richards, Main and Griffiths (1998) undertook a detailed study of 162 patients with psoriasis to determine what psoriasis patients believe about their skin condition using the Illness Perception Questionnaire. Results from this study indicated that 60 per cent of subjects believed that stress was a major factor in the onset of their condition. Where there was a strong family history of psoriasis subjects were more likely to attribute their skin condition to genetic factors, particularly if their condition developed before age forty. On the whole, females were more likely to attribute the cause and exacerbation of their psoriasis to their own behaviour. In the same study, the majority of psoriatic patients indicated that the condition had a major impact on their lives and the ways in which they viewed themselves. Again females reported that psoriasis had a greater impact on their lives. In conclusion, Fortune *et al.* (1998) suggest that the patients beliefs about their skin condition may have little to do with how severe their psoriasis is, but very much more to do with the meaning they ascribe to the unpredictable course of their condition. These results confirm the view that individuals often respond to the difficulties of a chronic illness by constructing their own common sense model of their condition (Weinman, Petrie, Moss-Morris and Home, 1996).

1.2.5 Anxiety, Depression and Anger in Psoriasis Patients

In a comprehensive review of the psychosocial impact of psoriasis, Wahl (1997) suggest that exposure to the physical features of psoriasis including itching, scaling and pain, has significant physical, emotional and social consequences. In a study by Fried, Friedman and Paradis (1995), more than half the outpatients who participated were rated as having moderate to extreme levels of anxiety, depression and anger. These results were not restricted to periods during skin flare-ups, with high scores reported during periods of remission. Studies of inpatients have found subjects to be more severely affected (Polenghi, Moloniari, Gala, Guzzi, Garutti and Finzi, 1994; Mazzetti, Mozzette and Soavi, 1994). Hughes *et al.* (1983) found that 33 per cent of dermatology inpatients and 15 per cent of outpatients had high scores on standard measures of depression. Symptoms of psoriasis, such as disfigurement, stigma and the inconvenience associated with the disease, are implicated in the onset of the depression.

1.2.6 Disability in a Non-treatment Seeking Population

Prevalence of psoriasis is thought to be about 1-2 per cent of the population in Britain. However, only 3 per cent of this group see a dermatologist, 17 per cent are treated by their general practitioner alone and the other 80 per cent do not consult any medical practitioner (Hunter *et al.* 1989). As the majority of studies focus on dermatology inpatients and outpatients, O'Neill and Kelly (1996) set up a study to examine those psoriasis patients who do not seek hospital consultations. This study compared the general health of people with psoriasis with the general population and evaluated the

Psoriasis Disability Index as a measure of disability in a community-based population. Results suggested that people with psoriasis in the general population suffer serious disability in many aspects of daily life, in comparison with controls. Although, the mean scores on the Psoriasis Disability Index were significantly less than in a hospital based study, there was a significant negative correlation with all variables on the General Health Questionnaire and the Psoriasis Disability Index. The results suggest that people with psoriasis perceive themselves to be less healthy than the general population and consequently general practitioners should be wary of underestimating the degree of distress a skin condition such as psoriasis can cause.

1.2.7 Summary

From this brief summary, examining psoriasis and psychological influence, it is clear that a high percentage of individuals experience psychological difficulties as a consequence of having psoriasis. Although the research is not clear about the nature and degree of stress required to impact on psoriasis, the evidence indicates both treatment and non-treatment seeking populations are affected. The following section will discuss these issues in relation to eczema.

1.3 ECZEMA

1.3.1 What is Eczema?

The terms dermatitis and eczema are used interchangeably (Docherty, 1987). Often they are preceded by 'atopic', but all refer to the same condition. As with psoriasis, the aetiology of eczema remains virtually unknown. Eczema is often described as a disease of delayed type allergy with resulting clinical features on the skin. Although there is strong evidence for genetic factors, there is a growing body of evidence that indicates a multi-factorial aetiology that includes psychological factors (Ehlers, Stangier and Gieler, 1995; Shirta, Nishitani, Fujino, Takano and Kiriike, 1996). Prevalence figures are quite varied; Faulstich and Williamson (1985) report that between 7 and 24 individuals per 1000 experience symptoms of eczema, whereas the National Eczema Society (1997) report prevalence rates of 2 to 10 per cent in adults and 5 to 15 per cent in school age children. Atopic eczema is the most common variant of the disease, and although it is mainly a disease of childhood, it will continue into adulthood for approximately 10 per cent of subjects (Herd, Tidman, Ruta and Hunter, 1997). In adulthood, eczema is characterised by dry and lichenified eruptions with scaling and erythema (Faulstich and Williamson 1985). As eczema is usually accompanied by a severe itch-scratch cycle, many sufferers report sleep disturbances, difficulties in concentrating and irritability, which aggravates their symptoms creating a vicious circle.

1.3.2 Medical Treatment of Eczema

Steroid hormones, anti-allergic and anti-pruritic agents are generally used to treat the disease. Some patients worry about the side effects which may result from treatment and the symptoms, which may restrict daily life (Shirta *et al.* 1996). In addition eczema patients are often advised to avoid certain chemical products such as biological washing powders, or soaps which may cause irritation to the skin. Due to the itch-scratch cycle, secondary infection is a common problem in eczema and is usually treated with antibiotics. As with psoriasis, many of the treatments available are time consuming to administer, unpleasant and messy, frequently with unwanted side effects. This clearly has implications for psychological wellbeing, particularly if the disease is chronic.

1.3.3 Psychological Factors in Eczema

Among skin disorders with a suspected somatic component, eczema is the condition most frequently cited (Faulstich and Williamson, 1985). However, reports describing the psychological state of patients with eczema are quite limited and generally tend to focus on one particular symptom, usually anxiety or depression (Hashiro and Okumara, 1997). This is a considerable contrast to the expansive literature examining psychological factors in psoriasis, as reviewed above. Existing studies mainly consist of clinical case examples and theoretical speculation, rather than systematic empirical and experimental observation (Keller, Zalewski, Carmody and Livingston, 1996). It may be the case that eczema has traditionally been viewed as a disease of childhood. Consequently, the effects of having eczema in adulthood have largely been ignored.

1.3.4 Anxiety and Depression in Eczema

The majority of studies find that both children and adults suffering from eczema have a higher anxiety level than non-sufferers (Linnet and Jemec, 1999). Hashiro and Okumura (1997) examined both anxiety and depression with somatic symptoms in a comparison between a group of patients with atopic dermatitis and controls, and between different degrees of severity. They found the experimental group to have greater depression ratings and to be more prone to somatic symptoms than controls. In relation to anxiety, no differences were found between the experimental and control groups. These results contradict with earlier findings by Ginsburg and Link (1993), that reported atopic dermatitis patients as frequently presenting as chronically anxious. Differences may be explained by the different experimental populations, adults in the Ginsburg study and adolescents in the Hashiro and Okumura study. Additionally cultural variations between the populations studied may account for differences found. The authors further examined the role of psychological state in atopic dermatitis, by comparison of psychological measures with biological/ immunological markers (Hashiro and Okumura, 1998). The results suggested that patients with moderate to severe skin conditions scored higher on psychological measures and showed lower biological markers than controls. The authors suggest that these results confirm the possible role of psychoimmunological factors in skin disorders.

In a more recent study, Linnet and Jemec (1999) examined the hypotheses that eczema patients would have higher anxiety and a lower quality of life than a control group. As the literature has often led to contrasting results, as discussed above, the authors

examined the possible relationship between eczema severity and particular components of anxiety. Subjects in this study were all adults. Results supported the hypotheses that eczema patients had higher anxiety scores and lower quality of life than controls. Severity of eczema was found to show greater relationship to items relating to care and management on quality of life measure, than on items relating to psychological factors. Consequently, the authors conclude that psychological assessment is especially important in differentiating the patients in need of psychological treatment, whereas dermatological treatment may help in reducing general anxiety levels.

Shirta *et al.* (1996) studied 64 outpatients with severe atopic dermatitis using the General Health Questionnaire and tested subjects pre and post treatment, in a comparison with healthy controls. Results indicated that patients were markedly disturbed in all areas measured before treatment; somatic symptoms, anxiety and worry, social dysfunction and despondency, and depressed mood. Scores were significantly reduced on all scales following improvement in skin condition. The authors suggested that psychological support for patients with atopic dermatitis should become a crucial part of treatment.

1.3.5 Disability in a Non-Treatment Seeking Population

Although many eczema patients, as with those with psoriasis, are treated in a hospital setting there is a large non-treatment seeking population with symptoms of eczema. Keller *et al.* (1996) looked at this non-treatment seeking population as part of larger study of Vietnam veterans. In a comparison of eczema sufferers with a group of tinea

sufferers (a fungal skin infection thought to be unrelated to psychological factors) and a control group, no significant difference were reported in terms of prevalence of anxiety, depression, hostility or levels of social support. Overall anxiety was reported in only 16 per cent of subjects compared to estimates of 26 to 63 per cent in previous studies. Depression rates are also considerably lower in this study. The authors suggest that subjects who seek treatment may be seeking relief from psychological symptoms as much as, or more than, the dermatological symptoms. Methodologically it is difficult to draw any firm conclusions from this study given the restrictive population of male veterans' aged 40 to 50. Further research is required to further examine the differences between treatment seeking and non-treatment seeking individuals in a more representative population.

1.3.6. Summary

Although research examining individuals with eczema has not been as extensive as in psoriasis, the same issues are clearly applicable to both. The causes of stress and other psychological difficulties in individuals with eczema and psoriasis are often associated with the stigma of having a skin disease. Research in relation to stigmatisation is discussed below.

1.4 EXPERIENCE OF STIGMATISATION

1.4.1 Definition

Ginsburg and Link (1989) define stigma as a biologic and social mark, that sets a person off from others, is discrediting and disrupts interactions with others. In relation to social stigma, Gupta, Gupta and Watteel (1998) suggest the term implies a mark of social disgrace, which manifests due to society's unwillingness to accept or approve of individuals with skin disease.

1.4.2 Background

Although there is a wealth of research exploring the effects of stigmatisation in other medical and psychological complaints such as epilepsy, Human Immunodeficiency Virus and mental illness, research in dermatology is limited. Ginsburg and Link (1989) attribute this lack of research to the conflicting views between patients and their dermatologists. In a study by Baughman and Sobel (1970), comparing patient and dermatologist views of the consequences of having a skin condition, patients ranked embarrassment over their appearance as the most significant consequence, whilst dermatologists ranked this as the least important outcome. There has been a growing awareness of the issue of stigma in dermatology over the past thirty years, but there continues to be a lack of systematic research in the area. Although frequently mentioned in relation to quality of life and consequences of having a skin disease, there have been few studies which specifically address anticipation of and actual experience of being

stigmatised. As mentioned earlier (section 1.1.2), many individuals will develop their skin condition before they are thirty. As the visibility of skin conditions can be a crucial factor in an individual's psychosocial development, it is likely that actual or anticipated experience of stigma will also play a crucial role in this psychosocial development.

1.4.3 Experience of Stigma in Dermatological Conditions

Literature examining stigma experience in the two skin conditions, eczema and psoriasis explored in this study, is limited. The majority of the research has focused on psoriasis and has been carried out by Ginsburg and Link (1989; 1993) in the United States. In the development of their questionnaire exploring stigma experience in psoriasis patients, 100 adults both inpatients and outpatients participated in their study (Ginsburg and Link, 1989). The research was centred on the development of a 33-item questionnaire measure. The data collected suggested there are six dimensions associated with stigma. These are sensitivity to the opinion of others, anticipation of rejection, feelings of being flawed, guilt and shame, secretiveness, and positive feelings. Results concluded that many individuals do report feeling stigmatised by their skin condition but that this is not a universal experience. In relation to the course of the individual's skin disease and stigma experience, three main points emerge from this research. These are outlined below.

1. Being older at the onset of psoriasis protects against anticipating rejection, feeling sensitive to the opinions of others and feelings of shame and guilt.

2. The longer an individual has experienced the illness the more likely they are to show less guilt, shame and secretiveness.
3. Findings clearly indicated that those with an early onset tend to show greater vulnerability to reporting stigmatisation.

Being secretive was identified, by Ginsburg and Link (1993), to be one of the most important components of daily experience of an individual with psoriasis. Evidence of wearing concealing clothing and avoidance of situations where skin lesions could be disclosed is particularly evident. This secretiveness did appear to be less apparent in the participants who were currently being treated as inpatients. The authors suggest this may be related to the environment of a ward setting where everyone has a skin condition and consequently inpatients may feel more comfortable about revealing their skin condition. It may have been expected that individuals with greater severity of psoriasis would report greater stigma experience. Surprisingly, this study reported extent of bleeding as the strongest predictor of feeling stigmatised. This is a perhaps unexpected result as bleeding is not usually a significant factor in psoriasis.

In a more detailed report of this study Ginsburg and Link (1993) focused on two dimensions of the stigma questionnaire, sensitivity to opinion of others and anticipation of rejection. Results indicated that there was a high correlation between feeling rejected due to psoriasis and problems at work, seeking professional help and alcohol consumption. In conclusion, the authors suggest these results reflect observations that people may act out their distress without being consciously aware of their feelings.

They also anecdotally report that rejection experiences are not always overt and that averting a glance or avoiding hand-shakes can be just as devastating as outward acts of rejection. Unfortunately, this study focused on direct acts of rejection such as being asked to leave a public situation, such as a swimming pool. As a consequence of such rejection experiences, Ginsburg and Link (1993) postulate that patients who anxiously anticipate rejection will very often avoid interpersonal situations or public places where they may be stigmatised. In turn, a vicious circle may develop with anticipation of rejection and avoidance of social situations influencing the course and severity of their skin condition. Consequently Ginsburg and Link (1989, 1993) emphasise the importance of provision of psychotherapy or support groups as a means of helping individuals cope with the stigma experience.

In a more recent study Gupta, Gupta and Wattell (1998), studied the stigma experience, by examining the deprivation of social touch that validates social rejection of patients with psoriasis. In this inpatient study, 137 consecutive patients were classified as belonging either to the stigmatised group or non-stigmatised control group on the basis of a question asking if they had experienced a situation in the past month where someone had overtly avoided touching them. Clearly this also misses individuals who may have experienced more subtle forms of social stigma such as avoided glances, particularly as those reporting no experiences in past month were used as the control group. Twenty-six per cent of participants in this study reported an episode in the past month where someone had made an obvious effort not to touch them. As mentioned earlier, inpatients in the Ginsburg and Link (1989) study reported less stigma

experience, consequently inclusion of an outpatient group in this study may have yielded a higher percentage of individuals reporting stigma experience. It was notable in this study that all but one of the subjects in the stigmatised group had one part of their body affected with psoriasis that was visible in social interactions. However, those reporting deprivation of social touch did not necessarily have psoriasis affecting a body region that is frequently touched in social interactions, such as hands or forearms. Of the psychological measures the comparing stigmatised group with the non-stigmatised group, depression scores were significantly higher in the stigmatised group. This is particularly important, given that a previous study (Gupta and Gupta, 1998) reported psoriasis to be associated with greater incidence of suicide.

1.4.4 Measurement of Stigmatisation

General measurement of stigma experience is limited to small studies and questionnaires developed for use with restricted subject groups. As described above, Ginsburg and Link (1989) developed a questionnaire for patients with psoriasis based on concepts relating to the nature of stigma and clinical experience of the researchers. As mentioned previously, the aim was to elicit feelings about expectations of rejection, experiences of discrimination, alienation, weakness, secretiveness, shame and guilt, and uncleanness. Interestingly, an additional factor, not predicted, related to positive attitudes. This factor proved difficult to interpret, as high despair on one factor did not preclude individuals reporting positive feelings about their skin condition.

To redress the sole focus on stigma experience in psoriasis, Schmid-Ott, Jaeger, Kuensebeck, Ott and Lamprecht (1996) developed the Ginsburg and Link questionnaire for use in a variety of dermatological conditions. Existing questions were adapted and a further 15 items were added. These items were based on previous research examining general stigma experience (Jones, Farima, Hastorf, Markus, Miller and Scott, 1984). Analysis of these items on patients with eczema, psoriasis and acne led to five distinct factors being identified, including the positive factor missed in previous research. These were self-esteem, retreat, rejection, composure (positive feelings) and concealment. Consequently, this measure can be administered to individuals with a number of differing skin complaints and allows comparisons across different symptomatology. To date there has been no study that examines differences in stigma experience between various skin conditions.

1.4.5 Summary

Research in the area of stigmatisation in relation to skin disorders is still in its infancy. The evidence clearly indicates that being stigmatised is a common factor for individuals with eczema and psoriasis. Experience of stigma is often discussed in relation to quality of life and this will be reviewed later. Ginsburg and Link (1989;1993) suggest that further research is required to understand the coping mechanisms of individuals, who feel stigmatised by their skin condition. The issue of coping in general and in relation coping with a skin condition is discussed below.

1.5 COPING

1.5.1. Background

There has been a wealth of research over the past thirty years examining how individuals cope with stressful situations as well as development of theories that adequately explain this. To date there has been little agreement over the conceptualisation and measurement of coping strategies (Aldwin and Revenson, 1987). Weinman, Wright and Johnston (1995) suggest there are two main areas of interest in relation to how individuals cope in stressful situations. The first stems from attempts to identify and explain the links between stress and health and the second from health psychology's attempts to understand the impact of illness. Research on coping indicates that levels of stress experienced depend on the way an individual copes with the different demands of the illness.

1.5.2. Definitions

Much of the research to date has focused on Lazarus's (1966) research into stress and coping. Lazarus and his co-researchers define coping as a person's constantly changing cognitive and behavioural efforts to manage specific external or internal demands that are appraised as taxing or exceeding the person's resources (Folkman, Lazarus, Dunkell-Schetter, DeLongis and Gruen, 1986). An individual's cognitive understanding of a particular encounter is appraised on two levels;

1. Primary appraisal is when a person evaluates whether they have anything at stake in the encounter
2. Secondary appraisal occurs when the individual evaluates, what if anything, can be done to overcome or prevent harm or to improve prospects for benefit.

Coping is the process of executing the response to primary and secondary appraisal.

In addition, coping has two widely recognised functions. Emotion-focused coping regulates stressful emotions, whereas problem-focused coping alters the persons environment in relation to whatever is causing distress. Consequently, as defined by Lazarus (1966), coping has three features. Firstly that it is process-orientated by focusing on what the person actually thinks and does in a specific encounter. Secondly it is contextual, in that it is influenced by the person's appraisal of the actual demands of the situation and their appraisal of resources available for managing these demands. Lastly, no assumptions are made about what constitutes good or bad coping, it is simply defined as a person's effort to manage demands faced.

1.5.2 Measurement of Coping

One of the most widely used instruments to measure coping is the Ways of Coping Checklist designed and then revised by Folkman and colleagues (Folkman and Lazarus, 1980; Folkman, Lazarus, Dunkel-Schetter, DeLongis and Gruen, 1986). This is a 51-item questionnaire which assess coping responses a person selects to manage a particular stressful situation. Two problem focused subscales were reported (planning problem solving and seeking social support). Six emotion focused subscales were also reported

(confrontative coping, distancing, self-controlling, accepting responsibilities, escape avoidance and positive appraisal). The Ways of Coping Checklist has been frequently modified for use with a variety of different medical conditions. Many of these have not reported the same factor structure (Weinman *et al.*, 1995). Consequently, Blanchard and Harper (1996) advise caution in the use of these measures, as many of the potential benefits have been lost through modifications to psychometric properties. These losses include the lack of empirical evidence for coping sub-scales, and the various scaling methods used leads to limitations in comparisons between studies.

Carver, Scheier and Weintraub (1989) suggested that Folkman and Lazarus's (1980) Ways of Coping Checklist is too simplistic in its measurement of coping strategies. Carver and Scheier (1994) suggest that differentiating between emotion-focused coping and problem-focused coping, as defined by Folkman and Lazarus (1980), is easy in principle but in reality there is often a considerable degree of overlap. The development of the COPE was an attempt to overcome some of the ambiguity of previous measures. In the development of the COPE, Carver *et al.* (1989) tested 978 subjects and results identified 13 distinct coping styles. The first of these styles is active coping. The authors suggest that this is very similar to the term problem focused coping, as described by Folkman and Lazarus (1980). Other problem-focused styles identified were planning, suppression of competing activities, restraint coping and seeking social support for instrumental reasons (e.g. seeking advice). Carver *et al.* (1989) suggest these additional problem-focused styles mainly function at the primary and secondary levels of appraisal, whereas active coping is the process of executing the response. Seeking

social support for emotional reasons is termed as emotion-focused coping but the authors acknowledge that this often co-occurs with the seeking of social support for instrumental reasons. Previous research (Folkman and Lazarus, 1980 and Vitalino, Russo, Carr, Maiuro and Becker, 1985) has suggested that other emotion-focused coping may be maladaptive. Carver *et al.* (1989) describe a further emotion-focused coping style, focusing on and venting of emotions. They suggest that this strategy impedes adjustment to a situation. Two other dysfunctional styles are identified on the COPE, behavioural disengagement and mental disengagement. Other sub-scales on the COPE measure positive reinterpretation and growth, denial and acceptance (the opposite of denial). The final sub-scale on the COPE measures turning to religion as a coping strategy.

Despite extensive attempts to measure coping strategy they, certainly do not exhaust all the possible ways an individual can react in a situation (Singer, 1984). Consequently, there is no guarantee that an experimentally suggested coping mechanism will be the optimal strategy for a particular situation. Research in relation to coping with chronic illness in general, and more specifically with psoriasis and eczema, is discussed below.

1.5.3 Coping with Chronic Illness

Shannon (1996) defines chronic illness as a condition that continues for six months or more and requires ongoing medical management. In contrast to acute illness, in chronic illness the likelihood of cure is low and symptom management rather than cure is the medical goal. Individual differences in reaction to chronic illness exist, with some

adults being more distressed than others. A critical assumption of current conceptions of coping is that coping strategies may have different consequences when used in response to different types of stress. Thus, the effectiveness of any given strategy depends upon its appropriateness for the particular stress faced (Felton, Revenson and Hinrichsen, 1984). In a review of studies of coping and chronic illness, Felton *et al.* (1984) found results to be mostly anecdotal or single case studies of specific illness. Depending on the definition of coping and the nature of the illness studied, typical coping strategies identified included denial, selective ignoring, information seeking, reminiscence about former good times, learning specific illness-related procedures, blaming others or seeking comfort from others. To eliminate the focus on a specific illness, the Felton *et al.* (1984) study focuses on comparison of the coping paradigm in four different illnesses. They concluded that there are no significant differences in coping strategies used by individuals with different illnesses. However, a significant relationship was found between measures of adjustment and coping strategies of wish fulfilling fantasy, emotional expression and self blame, which suggest that individual coping effects are not altogether positive. Using such strategies did not appear to promote acceptance of illness nor protect the individual from feeling depressed and consequently the authors suggest that overall emotion-based coping is related to poorer adjustment. This view is supported by Maes, Leventhal and DeRidder, (1996), who suggest that a coping style which is characterised by being active, expressive and thinking positively results in significantly higher levels of physical and psychological functioning. More positive scores on clinical measures of disease and higher levels of psychological well being usually reflect this. This is a particularly important point as long term physical health

can be a consequence of emotional state and, if coping strategies are ineffective, further deterioration of physical health may be the outcome. Consequently, a vicious cycle of illness-based stress, ineffective coping and poor emotional adjustment may develop.

1.5.4. Coping with Eczema and Psoriasis

Few studies have been conducted in the area of coping with stresses associated with having psoriasis (Wahl, 1997) and to date there does not appear to have been any research examining coping in individuals with eczema.

Studies examining specific coping strategies are limited. In one of the earlier studies, Coen (1976) examined ways in which individuals with psoriasis dealt with their skin condition. She identified that individuals with psoriasis tend to use behavioural strategies, such as concealment and avoidance of the unpleasant reactions of others, above other psychological defence mechanisms. Coen (1976) also identifies other frequently used coping behaviours such as drinking alcohol, joking about their condition and comparing it with other diseases that they perceived to be worse. In a more systematic exploration of coping in psoriasis sufferers, Taylor and Buckwalter (1988) examined the frequency of emotion focused strategies and problem solving approaches used, and the relationship between biographical data and the use of particular coping devices. Seventy subjects participated in the study, which used the Jalowiec Coping Scale (Jalowiec and Pares, 1981). This coping measure classifies 40 specific coping strategies as either problem-orientated or emotion-orientated. Results suggest that individuals with psoriasis use a variety of coping strategies and that each of the 40

strategies was used by at least one of the participants. The most frequently used methods in this study were control, objectivity, finding different solutions to the problem and information seeking to enhance the process of acceptance and problem solving. Using open-ended questions about actual strategies used, the authors identified coping strategies not mentioned in the questionnaire. These included concealment, education of others about the disease, and seeking of appropriate and effective treatment for their skin condition. In comparing demographic data with coping scores, differences were noted on two variables. Younger individuals, 18-40 years, were more likely to use both problem and emotion orientated strategies than older age groups. Significantly more emotion-focused mechanisms were used by the females in the study. Further research is required to support these findings, especially as there has been no attempt to categorise methods used, other than in broad terms of being problem or emotion-focused strategies. Frequently, the assumption is made that poorer outcome is experienced when emotion focused strategies are used, but further research is required to confirm this in individuals with psoriasis.

Other studies have attempted to compare coping mechanisms used across varying chronic medical conditions. Scharloo, Kaptein, Weinman, Hazes, Willems, Bergman and Rooijmans (1998) examine coping styles and illness perception to explain functioning in individuals with psoriasis, rheumatoid arthritis and obstructive pulmonary disease. Coping was measured using a Dutch coping inventory (Schreurs, P., Tellegen, B. and Van de Willige, G., (1984). The seven sub-scales of this measure explore seeking distraction, expressing emotions, fostering reassuring thoughts, passive coping

and active coping. Results confirmed previous research indicating that passive coping is associated with poorer outcome while seeking social support and belief in controllability reflected a better outcome. The results also suggested that illness representations have a significant and direct effect on functioning while this is not mediated by coping strategies used. The authors reported that, in relation to illness perception, the patients who believed that their psoriasis was likely to last a long time and have serious consequences were found to be functioning less well. Scharloo *et al.* (1998) suggest that interventions aimed at increasing an individual's personal control, and changing beliefs about the course of the illness, could be associated with general changes in overall psychosocial functioning.

1.5.6 Summary

The concept of coping is complex and difficult to define. Research examining coping in relation to chronic illness generally, concludes that coping style can influence the outcome of an individual's illness. Research into coping in skin diseases is clearly lacking. One area where there has been an expansion in research in dermatology is in relation to quality of life as discussed below. It has been suggested that quality of life is linked with both experience of stigma and coping mechanisms.

1.6 QUALITY OF LIFE IN DERMATOLOGY

1.6.1 Background

In the past twenty-plus years, there has been a wealth of research examining quality of life issues. A review of this general literature would be impossible within the context of this study. Both general and specific quality of life measures focus on the impact of disability and handicap caused by specific impairment. Finlay and Ryan (1996) define these three features in reference to dermatological conditions. Impairment refers to the effect of the disease process on a diseased organ, such as the persisting fissures and scaling of the skin found in psoriasis and eczema. Disability describes the functional effects of this impairment, such as an inability to use a keyboard due to pain or altered sensations in the hand with dermatitis. Handicap therefore describes the effect on the patient's normal functioning as a consequence of the disability. In the example of the keyboard operator, this may involve no longer being able to continue to work. The authors indicate that these terms often become confused within the literature. Although general health measures have proved useful in research, dermatology-specific measures are required for day to day clinical use (Finlay and Ryan, 1996). Methods of measuring disability caused by skin disease are required for a variety of reasons. These include the need to assess the effectiveness of new therapies, to allow comparisons between skin diseases, and audit the effectiveness of clinical outcomes (Finlay and Khan, 1994). Quality of Life measures could also be viewed as an effective means of identifying individuals with marked disability, who may benefit from psychological approaches.

The following review will concentrate on the concept of quality of life within dermatology. Despite the obvious impact having a chronic skin condition has on an individual's quality of life, research in dermatology has lagged behind similar research in other medical conditions (Finlay and Coles, 1995; Morgan, McCreedy, Simpson and Hay, 1997).

1.6.2 Disease Specific Quality of Life Measures

In reference to the conditions examined in the current study the Psoriasis Disability Index (Finlay and Khan, 1994) was one of the first disease specific measures to examine quality of life issues. The Psoriasis Disability Index (PDI) is a 15 item measure relating to psoriasis related problems experienced in the past four weeks. Items specifically address self-reported disability in areas of daily activities, employment, personal relationships, leisure and treatments effects. The measure was validated against general health questionnaires such as the UK Sickness Impact Profile (Finlay and Kelly, 1987; Finlay, Khan, Luscombe and Salek, 1990).

Finlay and Coles (1995) undertook an extensive study using the Psoriasis Disability Index to quantify levels of disability experienced by patients with psoriasis and the value individuals placed on their disease. This was a UK wide survey with dermatologists asking patients to complete the PDI, rate psoriasis against a comparable disease and to indicate the importance placed on their skin disease (time prepared to treat, cost). Results indicated that psoriasis has a significant effect on perceived quality of life. Of those patients who were currently employed (59.3 per cent), a mean number of 26 days

per year were lost due to problems with their psoriasis. Of those participants who indicated they were retired, 33.9 per cent attributed their retiral to their psoriasis. In patients who also suffered from one of the comparable diseases (diabetes, asthma or bronchitis), the predominant response was that having psoriasis was worse than having the other illness. Interestingly, the majority of those without a comparative disease thought it would be worse to have a disease other than psoriasis. This perhaps reflects the view that patients with psoriasis frequently minimise the extent of their illness (Metz and Jemes, 1996). In relation to the value placed on the skin condition, 49 per cent of the patients indicated that they would be prepared to spend two to three hours each day on treatment, if this would result in normal skin for the rest of the day. Nearly all the patient in the survey indicated that they would prefer a cure rather than a gift of one thousand pounds. However, if they had perhaps known the true costs of treating psoriasis a different picture may have emerged. Cork (1993) calculated that the overall cost of drug therapy for severe psoriasis was over £800 per annum, PUVA therapy was over £500 per treatment course, and a single two week admission to hospital costs nearly £3,000 for the bed alone. Costs of eczema patients are likely to be very similar.

The Psoriasis Disability Index has also been used to compare the impact of clinical severity, anatomical location and treatment in psoriasis (Fortune, Main, O'Sullivan and Griffiths, 1997b). This study also examined psoriasis related stress on patients' physical and mental health and on areas of disability in everyday life. Results indicated that severity of psoriasis, duration of skin condition, gender and anatomical locations were unrelated to impairment in any specific area of quality of life. However, it was reported

that stress from anticipating the reaction of other people to their psoriasis, contributed more to the variance of patients' disability in everyday life than any other variable. Such evidence links to the research exploring stigmatisation in skin conditions and provided evidence that actual or perceived stigma can be one of the most debilitating factors in having a skin disease.

1.6.3 General Dermatology Quality of Life Measures

In order to assess quality of life across a number of dermatological conditions, Finlay and Khan (1994) developed the Dermatology Life Quality Index (DLQI). This was based on previous research, mainly the Psoriasis Disability Index (Finlay and Kelly, 1987; Finlay *et al.*, 1990) and the Acne Disability Index (Motley and Finlay, 1992). In the development of the DLQI, 120 patients with different skin diseases were asked about the impact of their disease and its treatment on their lives. The DLQI was developed based on the answers received and then tested on 200 consecutive outpatients. It was hoped that the measure would provide a compact assessment (10 items) applicable to routine clinical practise. As expected the DLQI, confirmed that atopic eczema, psoriasis and generalised pruritus have greater impact on quality of life than other skin conditions such as warts or skin cancers.

A few studies have since been undertaken using this measure, including a study focussing on quality of life in atopic dermatitis (Finlay, 1996; Linnet and Jemec, 1999). The DLQI has also been used to measure effectiveness of inpatient treatment (Kurwa

and Finlay, 1995) and has been adapted for use with children (Lewis-Jones and Finlay, 1995).

In the Linnet and Jemec study (1999), the DLQI was used in an investigation of the relationship between the severity of atopic dermatitis, anxiety and life quality. As reported earlier, atopic dermatitis patients had significantly lower dermatological life quality than a control group. Interestingly, this study found some seasonal differences in responding on the DLQI, which suggests that life quality can fluctuate in varying circumstances and with improvements in the skin condition. In this study the numbers are perhaps too small to draw any firm conclusions, but it suggests that results should be treated with caution if subjects are tested at different times of the year and at differing stages in treatment. Although severity of eczema and trait anxiety were significantly related to items on the DLQI, in this study they were not related to each other. Severity of the eczema related more to items of practical care and management, whereas Trait Anxiety showed a more significant relationship to items regarding intimacy and body exposure. However, given the limited number of questions relating to these items, further research would be required to confirm this finding.

With the exception of Finlay and Khan's (1994) questionnaire, measures relating to quality of life in dermatology have largely been disease specific (Finlay & Coles, 1995; Fortune, Main, O'Sullivan and Griffiths, 1997a; Motley & Finlay, 1992). The majority of these questionnaires are limited in examining the psychosocial impact of having a chronic skin condition. To redress this, Morgan *et al.* (1997) developed the Dermatology Quality of Life Scales (DQLS) with a greater emphasis on the

psychosocial domain. The measure was developed by asking 50 individuals to rate the ways in which their skin condition affected them in terms of feelings, personal relationships, daily and social activities. From this, a scale of 17 psychosocial and 12 activity items were identified. Testing, on individuals aged 13 to 84 years of age on a variety of skin conditions, including psoriasis, eczema and acne, revealed high internal consistency and construct validity. The authors concluded that the result were comparable to many other disease-specific measures. As predicted, psychosocial scores were higher for eczema and psoriasis than in other conditions, such as skin cancer. Younger individuals tended to have higher psychosocial scores. Results also confirmed the findings of other studies, which suggest that the psychosocial impact is greater for women than men. This measure consequently overcomes the recognised problem of generic health status measures to the effects of specific diseases. This measure was used in the current study.

1.6.4. Qualitative Approach to Measuring Quality of Life

Studies that qualitatively explore the handicap that results from skin disease are rare. Jowett and Ryan (1995) used an interview method to explore occupational, social and emotional functioning in patients with eczema, psoriasis and acne. Interviewees were asked detailed questions about the history extent, and severity of their condition, their employment experiences (including any difficulties caused by their skin disease), any limitations on their leisure activities, and their subjective responses to the disease. The results focus on the negative impact skin disease has on the interviewees' lives. Negative experiences were reported across all the areas studied. This study could be

criticised for a failure to emphasise any positive coping styles adopted to cope with difficulties faced. With such detailed information, the authors should have been able to explore differences across the three conditions rather than analysing them together. The authors concluded that it is important to improve the psychological and social environment of those with skin disease, by educating the general public and developing techniques to help the patient cope effectively with difficulties faced.

1.6.5 Summary

It is clear that the concept of quality of life is especially relevant in the study of skin disease. It seems that one group of researchers have conducted much of the work in this area. Further research is required to refine existing measures with more attention to psychosocial factors and perhaps links to common themes explored in the literature on stigmatisation. There appears to be scope for the use of quality of life measures in evaluating psychological methods of treatment. As much of the research highlights the need for psychological approaches, existing approaches are described below.

1.7 PSYCHOLOGICAL INTERVENTION IN DERMATOLOGICAL CONDITIONS

1.7.1. Background

Given the recent increases in the research examining quality of life and stigmatisation issues in dermatology it would be expected that psychological approaches would have

emerged to deal with difficulties identified. Although treatments have been reported, the majority involve small numbers with little consistency to allow comparison between treatments. It has been recognised that psychological factors influence the outbreak and exacerbation of many skin conditions but, despite this, dermatology as a profession has not always recognised the need for psychological interventions (Beaman and Luzzato, 1988). Some authors have suggested that the incorporation of psychological models into dermatology is of far greater importance than other specialities such as cardiology, and cosmetic surgery, where extensive research has been carried out (Van Moffaert, 1982). This does not only apply to medical settings. Others have suggested that psychological approaches are just as important in managing dermatological conditions in a primary care setting (Mackie, 1991). This is particularly relevant considering the small numbers of individuals with skin conditions that seek referral to dermatologists and the large numbers seeking help from their general practitioner or coping alone.

Below, some of the varied psychological treatment studies in eczema and psoriasis are discussed. Although many of the psychological therapies overlap, and in some cases are identical, there are no studies that compare or contrast the psychological treatment of the two conditions together. In a general review of psychological approaches, the main treatment options identified were relaxation training, biofeedback, hypnosis, operant conditioning and cognitive-behavioural therapy (Tsushima, 1988). Given the lack of well-controlled and replicated studies to date, it is crucial that current levels of knowledge in relation to these treatments in dermatology are viewed as tentative.

1.7.2 Psychological Approaches to Psoriasis

The literature pertaining to psychological treatment approaches in psoriasis is often very varied and at times vague. Much of the research has focused on means of reducing the symptoms or dealing with the stress thought to exacerbate the condition.

In a small study exploring the use of hypnosis, subjects were assigned to a hypnosis only group, hypnosis plus PUVA treatment or PUVA treatment alone (Boncz, Farkas and Hunyadi, 1990). Positive results were reported, with hypnosis being implicated in the termination of unpleasant symptoms such as itching, tenseness of the skin and sleeping difficulties. In terms of improvement in skin condition, the group, which had PUVA and hypnosis, fared best. In a study with only 27 participants, it is again difficult to draw any firm conclusions. It would be interesting to know if there were any variations in responses to hypnotic susceptibility and suggestion across the variety of measures.

In a larger scale study, (Zachariae, Øster, Bjerring and Kragballe, 1996), 51 patients were randomly assigned to a treatment or to a control group. Treatment lasted twelve weeks and included group work plus individual psychotherapy sessions. Interventions included stress management, guided imagery and relaxation. All outcome measures were based on dermatological indices, skin severity and immunological mechanisms. Results showed a slight but significant improvement on all dermatological measures for the treatment group in comparison with the control group. Although the authors concluded that the intervention had a moderately beneficial effect on psoriasis activity, longer follow-up may have yielded results that were more positive. This study could

have also benefited from the inclusion of psychological measures, as other studies have suggested that a reduction in psychological distress does not necessarily correspond with improvements in skin condition.

Another study using a randomised time-series study, explored four approaches to the psychological treatment of psoriasis (Gaston, Crombez, Lassande, Bernier-Buzzanga and Hodgins, 1991). The two experimental groups were individuals receiving meditation, or meditation and imagery. The control groups were either placed on a waiting list or receiving no treatment. Treatment lasted twelve weeks. Numbers in each of the groups were very small, four or five. Four subjects showed improvement in their psoriasis as rated by a dermatologist, the rest did not deteriorate. The authors suggest reduction in symptom severity could be explained by individuals following explicit instructions to reduce symptoms or merely by the belief that they were being helped by the treatment. Clearly, a replication of this study using a far larger number of subjects is required to clarify this issue.

1.7.3 Psychological Approaches to Eczema

James (1995) suggests that there are a number of psychological approaches that can be offered to improve the quality of life in eczema sufferers. These include reducing itch levels by lowering sympathetic activity, use of behavioural methods to modulate scratching behaviour, stress management and counselling to help families and individuals cope. Obviously, the selection of suitable patients for such approaches is crucial, requiring development and utilisation of various screening tools. It has been

suggested that three types of patients with eczema and psoriasis can be identified. The first is those who are best helped by social interventions (e.g. education), a second group who benefit from stress management and a third group who require deeper attention to personal problems through psychotherapy (Beaman and Luzzato, 1988). To date, the therapeutic benefits of psychological interventions, beyond those of standard medical treatments, has received little attention in dermatitis (Ehlers, Stangier and Gieler, 1995).

Much of the research in eczema has focused on behavioural approaches particularly in the management of the itch-scratch cycle. More recently, there have been attempts to introduce cognitive-behavioural approaches to tackle the range of problems associated with having eczema. De L. Horne, White and Varigos (1980) present three case studies using a cognitive-behavioural approach to the management of eczema. The approach involved some general elements that included self-monitoring of eczema severity, identification and recording of cognitive and environment triggers to flare-ups, and relaxation training using imagery, and habit reversal. All three cases showed a post treatment reduction in symptom severity, increase in ability to control symptoms such as scratching, and a decrease in reliance on medication. As a small pilot study, it is difficult to make any firm conclusions about the effectiveness of the approach, especially given two patients received less than 10 sessions while the third received 33. The authors suggest a controlled treatment trial would be required to evaluate the different treatment components used in this study. In order to assess the value of psychological approaches in relation to standard medical treatments of skin conditions, Ehlers *et al.* (1995) developed a randomised control trial, exploring four psychological

treatments. The treatment groups consisted of a dermatological education programme, autogenic training as a form of relaxation, cognitive-behavioural therapy and combined education and cognitive-behavioural therapy. Results indicated that psychological treatments led to a significant and stable addition to treatment. At one year follow-up, all interventions with the exception of education alone, showed significantly larger improvements in skin condition than standard medical treatments alone. Improvements were accompanied by a reduction in the use of topical steroids. In addition, although none of these treatments targeted anxiety or depression directly, measures in these areas were decreased in all four groups post treatment.

1.7.4 Summary

The scope for psychological intervention is great but, to date, evaluation and development of techniques has been limited. Results look promising for cognitive-behavioural approaches in dermatology but more extensive research is required. As it has been suggested that coping style influences outcome in chronic illness, further work is perhaps required to provide interventions for improving coping mechanisms in skin conditions. Intervention is beyond the scope of this study but is discussed within the context of future studies.

1.8 PRESENT STUDY: AIMS AND HYPOTHESES

1.8.1 Aims

The study aims to examine the impact of having a skin disease on life quality and experience of stigma through replication of the findings of previous studies. In addition, a novel aspect of this present study was to examine coping style in relation to stigmatisation and quality of life, and to compare differences between individuals with eczema and psoriasis. Therefore, the hypotheses are divided into two sections exploring current research findings and the experimental hypotheses for this study.

1.8.2. Hypotheses

From the Research Literature

1. a. Females will report reduced quality of life in comparison to males.
1. b. Females will report greater stigma experience than males.
2. a. Younger age at onset and younger current age will have a negative impact on stigma experience.
2. b. Younger age at onset of skin disease and younger current age will affect of quality of life reported.
3. a. Greater visibility of skin disease will lead to greater impairment in quality of life.
3. b. Greater visibility of skin disease will lead to greater experience of stigma.

4. Levels of psychosocial distress will be lower in individuals who adopt active problem solving approaches to coping.
5. Levels of psychosocial distress will be higher in individuals reporting greater stigma experience.

Experimental Hypothesis

6. a. Individuals with psoriasis and eczema will report similar experiences of having a skin complaint (stigmatisation).
6. b. Quality of life will be similar for individuals with eczema and psoriasis.
7. Individuals who report high levels of stigmatisation will report similar coping styles.

CHAPTER 2 – METHOD

2.1 DESIGN

A between-groups design was used with measures of stigma experience (Experience of Skin Complaints), coping style (the COPE scale) and psychosocial problems (Dermatology Quality of Life Scales). Participants were placed in two groups according to their skin condition, either eczema or psoriasis. At the initial stages of this study it was hoped to have four groups to allow comparison between both inpatients and out patients with eczema and psoriasis. Due to time constraints, and smaller numbers of patients with eczema, than expected this was not possible. Previous research studies examining psychological factors in dermatology have tended not to distinguish between inpatients and outpatients or between skin conditions. Each participant was seen on at least one occasion. A sample of individuals volunteered to attend for an interview with the researcher, following completion of the questionnaire methods.

The Tayside Committee on Medical Research Ethics granted approval for this study to be carried out. Minor changes were requested for the patients' information leaflet, but no changes were made to the research design.

2.2 PARTICIPANTS

The participants were all current patients of the Dermatology Department at a large teaching hospital. Initially, 102 patients were approached and asked if they were willing to participate in the study. Thirty-one participants failed to return the questionnaire measures. Of the 71 questionnaires returned, seven were excluded as they did not fulfil the criteria, or the participant had failed to complete one of the

measures. This left 64 participants in the study. Thirty males and thirty-four females participated in the study. The majority of patients (n=59) were approached by the researcher to participate in the current study. The dermatology treatment nurse and the senior charge nurse in the photobiology unit approached the other five patients. Participants were placed in one of two groups according to their skin condition, psoriasis or eczema. The psoriasis group (n=39) included both inpatients (n=10) and outpatients (n=29). The second group consisted of patients with a primary diagnosis of eczema (n=25) which also consisted of inpatients (n=6) and outpatients (n=19). Participants in both the eczema and psoriasis groups were currently receiving treatment by physicians for their skin condition.

Criteria for inclusion in the study were:

- Adolescents and adults currently patients of the Dermatology Department¹
- Skin condition present for more than six months.

The main exclusion criteria was:

- An individual in current treatment in the Clinical Psychology Department

¹ The youngest participant was 15 and included due to sample size consideration after full parental and individual consent was obtained.

2.3 MEASURES

2.3.1 Experience of Skin Complaints (EoSC)

This is a 34-item scale developed by Schmid-Ott *et al.* (1996) to identify dimensions of stigma experience in patients with chronic skin disease. This scale expands a previous questionnaire designed by Ginsburg and Link (1989), that examines stigma experience in individuals with psoriasis. Five factors are identified in relation to stigma experience.

- 1) **Self-esteem:** This relates to interference of skin symptoms and self-esteem and includes feeling worthless, alone or unclean as a consequence of having a skin disease.
- 2) **Retreat:** This factor corresponds to outer appearance and situation-caused retreat. This describes feeling physically or sexually unattractive and avoidance of social situations when skin condition is bad.
- 3) **Rejection:** Rejection and devaluation items comprising of anticipated or experienced negative reactions from others.
- 4) **Composure:** This scale describes calmness and confidence in quality of life in spite of having a skin condition.
- 5) **Concealment:** The final scale comprises tendencies for hiding the diagnosis and keeping the skin condition a secret.

Scores can be obtained for each factor as well as a total experience of skin complaint score. Higher scores indicate a greater degree of feelings of stigmatisation. In the original study, items were scored on a six point scale from strongly agree to strongly

disagree. It was thought that a neutral midpoint would be more desirable and would not increase disagreement with the original study. Consequently, in this study responses are measured on a five point scale from strongly agree to strongly disagree, including a neutral midpoint (Appendix 1). For the original study, construct validity on the EoSC was assessed comparing interrelations with skin symptomatology, regions affected and social characteristics for 187 patients with eczema, psoriasis and acne. The internal consistency for each factor was calculated using Cronbach's Alpha (self-esteem = 0.87, retreat = 0.86, rejection = 0.87, composure = 0.76 and concealment = 0.76). The questionnaire was found to be a reliable and valid measure. Permission was obtained from the authors to use the EoSC in the current study.

2.3.2 COPE

Designed by Carver, Scheier and Weintraub (1989) the COPE is a comprehensive measure of coping and can be used to examine both situational (responses to a specific situation or period of time) and dispositional (typical responses to stressors) coping. In the current study situational coping was examined. The COPE was given with the instruction;

'We are interested in how people respond when they confront difficulties in their lives, such as having a chronic skin condition. This questionnaire asks you to indicate what you generally do and feel about having a skin condition'.

The COPE is a 52-item measure consisting of 13 distinct scales. These are outlined below.

- 1) **Active Coping:** taking action, and exerting efforts, to remove or circumvent the stressor.
- 2) **Planning:** thinking about how to confront the stressor, planning one's active coping efforts.
- 3) **Seeking Instrumental Support:** seeking assistance, information, or advice about what to do.
- 4) **Seeking Emotional Social Support:** getting sympathy or emotional support from someone.
- 5) **Suppression of Competing Activities:** suppressing one's attention to other activities in which one might engage, in order to concentrate more completely on dealing with the stressor.
- 6) **Turning to Religion:** increased engagement in religious activities.
- 7) **Positive Reinterpretation and Growth:** making the best of the situation by growing from it, or viewing it in a more favourable light.
- 8) **Restraint Coping:** passively coping by holding back one's coping attempts until they can be of use.
- 9) **Acceptance:** accepting the fact that the stressful event has occurred and is real.
- 10) **Focus on and Venting of Emotions:** an increased awareness of one's emotion distress and a tendency to discharge those feelings.
- 11) **Denial:** an attempt to reject the reality of the stressful event.

- 12) **Mental Disengagement:** psychological disengagement from the goal with which the stressor is interfering, through daydreaming, sleep or self-distraction.
- 13) **Behavioural Disengagement:** giving up, or withdrawing effort from, the attempt to attain the goal with which the stressor is interfering.

Since Carver *et al.* (1989) developed the COPE, two additional scales have been added, alcohol/drug use and humour. These are regarded as still being in exploratory stages and limited data is currently available on the validity of these scales although internal consistency is noted to be high (Weinman *et al.*, 1995).

There are separate scores for each of the 15 scales and these are calculated by adding the scores on four items that make up each scale. Scores range from 4 to 16 for each of the scales. The revised version of the COPE has 60 items in total (Appendix 2).

2.3.3. Dermatology Quality of Life Scales (DQLS)

The Dermatology Quality of Life Scales were developed by Morgan *et al.*, (1997) to assess the impact of skin conditions on the patient's psychosocial state and everyday activities. The scales were designed as a comprehensive measure of the impact of skin conditions on health related quality of life. The authors suggest that this measure is much more sensitive to the impact of skin problems than a generic health status measure, especially in the psychosocial sphere. The measure contains 29 items (17 psychosocial and 12 activities). Psychosocial items relate to embarrassment, despair, irritability and distress (anxiety and depression). Items on the activity scale relate to everyday tasks, summer, social and sexual activities. Each

item is rated on a five point scale: very slightly or not at all (0) to extremely (4). Scores are adjusted to be within the range of zero to 100. Higher scores indicate a greater impact on quality of life. The questionnaire was tested on 118 outpatients of a dermatology department and internal consistency was shown to be high (Cronbach's Alpha 0.92 for psychosocial items and 0.83 for activity items). Reliability was tested on 41 outpatients and showed good short-term test retest reliability. Construct validity was confirmed by the ability of the scale to identify clinically expected differences. Permission was obtained from the authors to use this questionnaire in the current study (Appendix 3).

2.3.4. Background Information

General information was collected via the patient information sheet (Appendix 4).

This included:

- Type of skin condition
- Age
- Length of time with condition
- Age at onset of skin condition
- Anatomical location of skin condition

It is well known that the objective measurement of skin condition severity is problematic, due to participants being recruited at different points in treatment and both psoriasis and eczema severity being subject to seasonal variation. Consequently, actual severity was not assessed in this study. Gupta *et al* (1998) suggest that the location of the skin condition may be a more valid measure. They

suggested that skin conditions which predominate in socially visual areas such as the face and hands should be classed as 'emotionally charged' regions in comparison to other parts of the body. As a crude measure, participants whose skin condition predominated on the face, head, hands and wrists were classed as 'emotionally charged' and those whose condition was mainly located on the arms, torso and legs were classed as 'not emotionally charged'. In addition a third category was included in this study for participants with both emotionally and non-emotionally charged areas of skin disease.

2.3.5 Semi-Structured Interview

The first fifty participants in the study were asked if they wished to participate further in the study by attending for a short interview. Of those who responded, (n=20) ten attended interviews either at the Clinical Psychology Department or were seen by the researcher in their own homes. The interviews all followed a similar outline, exploring problems associated with having a skin disease, personal experience of being stigmatised and general ways of coping (Appendix 5). Participants were asked specific questions in relation to the above issues, but were free to discuss personal experiences relating to their own skin conditions and any issues raised from completion of the questionnaire methods. The intention of conducting the interviews was to provide qualitative information to augment results from the quantitative measures.

2.4 PROCEDURE

Participants in the study were identified according to treatment location. The main settings were the dermatology ward, photobiology unit and the dermatology outpatient department, attached to a large teaching hospital. Suitable participants were identified by dermatology staff and then approached by the researcher and asked if they wished to participate in the study. As noted earlier, a small number of participants ($n=5$) were approached by the dermatology treatment nurse and senior charge nurse, and were not seen by the researcher. Participants were given an information sheet to read, explaining the nature of the study and encouraged to contact the researcher should they have further questions (Appendix 6). Due to the time constraints of dermatology appointments, participants were encouraged to complete the measures in their own time and return these via a self-addressed envelope. Participants, who were patients on the ward, returned the completed measures to ward staff in a sealed envelope. The consultant dermatologists were informed as to which of their patients had participated in the study. As not all participants in the study knew the name of their consultant, a complete list of subjects was retained by the researcher in case further information was required. As mentioned above, the first fifty participants were invited to participate further in the study by attending for a short interview (Appendix 7). These interviews took place in the participant's own homes, dermatology ward or at the clinical psychology department of the same hospital where they receive treatment. Appointments were arranged, whenever possible, within three weeks of completion of the questionnaire measures. An opportunity to discuss issues raised by the questionnaires was offered

during the interviews. Interviews, which were tape-recorded and fully transcribed, lasted between 20 and 50 minutes and were conducted by the researcher.

2.5 ANALYSIS OF DATA

2.5.1 Data Analysis

All statistical analyses were carried out using the Statistical package for Social Sciences (SPSS) for Windows 95, Version 9. Relationships between variables were calculated using between group t-tests, correlations and multiple regression.

In analysing the qualitative data, repeated readings of the transcripts suggested a number of ways that participants think about their skin conditions. These formed the themes around which the analysis was organised. Current literature, examining coping and stigmatisation issues, was also consulted to facilitate development of themes for analysis. Transcripts were coded for each of the identified themes.

2.5.2 Statistical Power

Following discussion with one of the Consultant Dermatologists and Charge Nurse in the Dermatology department, where the study took place, it was expected that at least 100 patients could be identified over the four-month period of the study. Allowing for the potential of the low response rate typically associated with questionnaire designs, the sample size was expected to be at least 30 in each group. Consequently,

a large effect size was anticipated. This satisfies with Cohen's (1992) criteria on statistical power.

CHAPTER 3 - RESULTS

3.1 DEMOGRAPHIC DATA

3.1.1 Exploration of data

Prior to statistical analysis, the data was explored. Where applicable, the data was explored for skewness and kurtosis. Significant results are reported at the <0.05 level and all significant results are reported in bold type.

3.1.2 Participants

One hundred and two individuals were approached and agreed to participate in this study. Two individuals refused. Respondents were asked to complete the questionnaires in their own time and return them at their next appointment, or directly to the researcher via a stamped addressed envelope. Inpatients returned questionnaires to nursing staff to be passed to the researcher. Seventy-one questionnaires were returned equating to a response rate of 70.3 percent. Seven of these respondents were excluded from the study, as they did not fulfil the criteria, mainly they had had their skin condition for less than six months, or did not complete all the questionnaire measures. In all sixty-four participants were included in the study.

Subjects were separated into two groups, based on their skin condition. In all, 39 participants were included in the psoriasis group and 25 participants included in the eczema group. Table 1 shows the frequency of male and female participants and where participants were receiving treatment for their skin conditions.

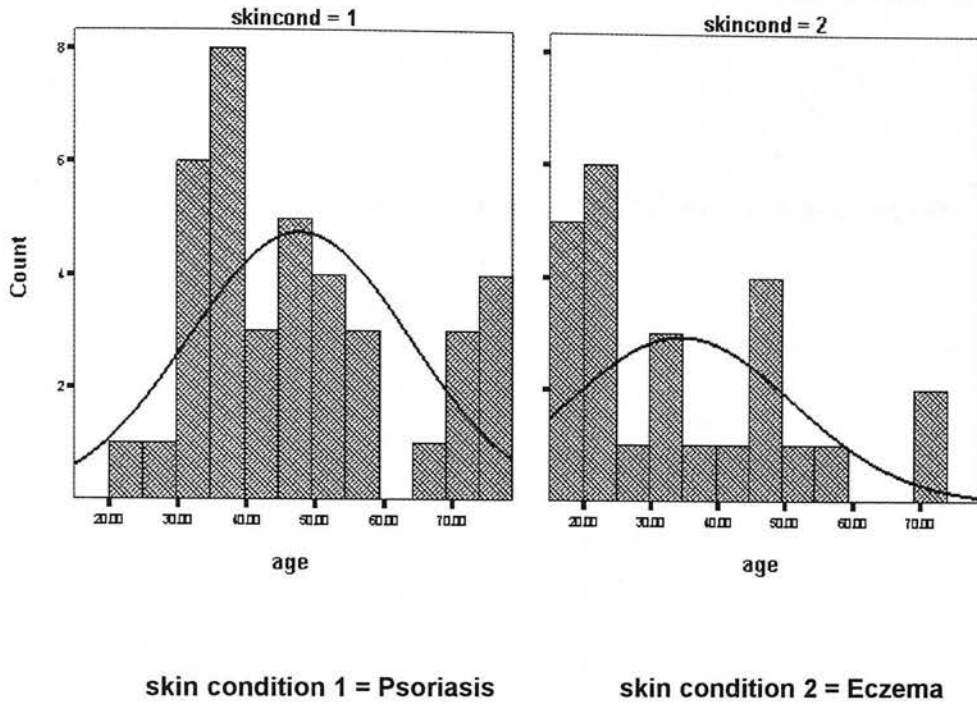
Table 1: Age and Location of Treatment

Skin Condition	Gender		Treatment Location	
	Male	Female	Outpatient	Inpatient
PSORIASIS	17	22	29	10
ECZEMA	13	12	19	6
Total	30	34	48	16

In the initial stages of the study, it was planned to separate the psoriasis and eczema groups further by differentiating between participants who were inpatients or outpatients at time of recruitment into the study. Due to the small number of suitable inpatients, this division was not completed.

3.1.3 Age

Both psoriasis and eczema can effect adults at any age. Figure 1 and Table 2 examine the mean age and distribution for each group in this study.

Figure 1: Histogram for Age in Psoriasis and Eczema Groups**Table 2: Mean Age in Psoriasis and Eczema Groups.**

Skin Condition	N	Mean	Minimum	Maximum	Std. Deviation
PSORIASIS	39	47.69	20	79	16.12
ECZEMA	25	34.44	15	74	16.73
Total	64	42.52	15	79	17.48

Figure 1 and Table 2 suggest that there may be some discrepancy between distributions for both groups. A between groups t-test was conducted to compare ages in both groups ($t = 3.16$, $df = 62$, $p < .01$, one-tailed).

It was expected that there would be differences in the mean age of onset between the two conditions, as eczema generally develops in childhood while psoriasis generally develops in adulthood. Figure 2 and Table 3 report the mean age of onset of skin condition for both groups.

Figure 2: Histograms for Age at Onset in Psoriasis and Eczema Groups

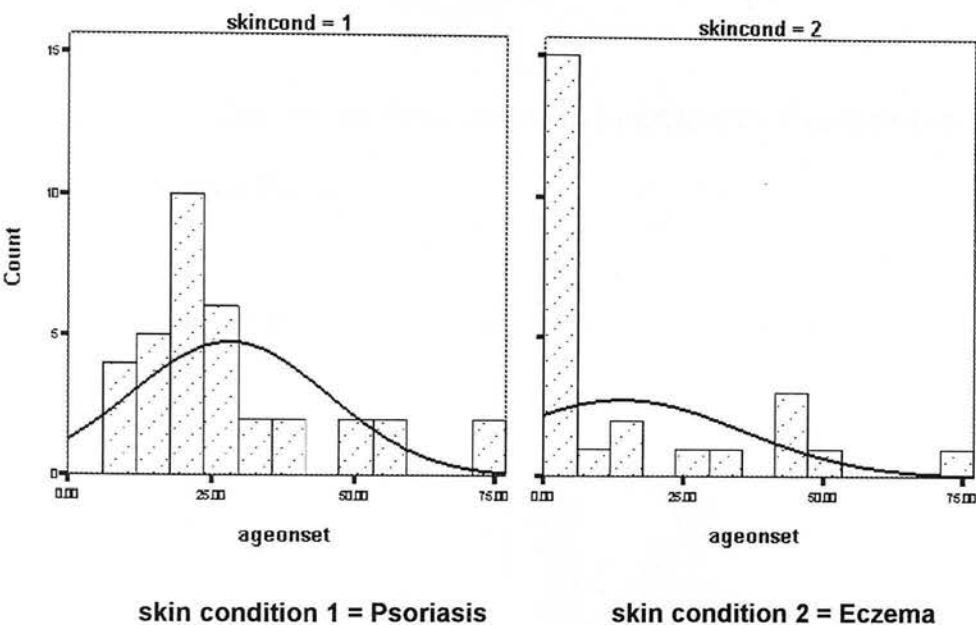


Table 3: Mean Age at Onset for Skin Conditions in Psoriasis and Eczema Groups

Skin Condition	N	Mean	Minimum	Maximum	Std. Deviation
PSORIASIS	35	28.12	8	77	17.42
ECZEMA	25	14.16	0	73	21.46
Total	60*	22.30	0	77	20.26

*Information on age at onset of skin condition was missing for four participants.

To establish if the differences between the two groups are significant a between-samples t-test was completed ($t = 2.78$, $df = 58$, $p < .01$, one-tailed).

Length of time an individual has had a skin condition may be an important consideration when analysing the effect of other variables. Figure 3 and Table 4 compare the distribution and mean length of time participants have had their skin condition.

Figure 3: Histogram for Time with Skin Condition for Psoriasis and Eczema Patients

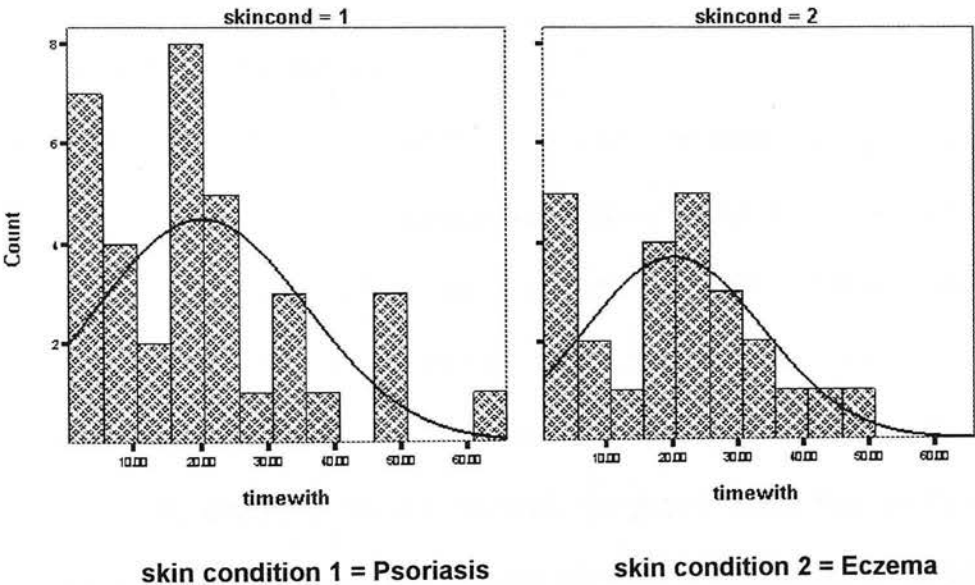


Table 4: Mean Length of Time with Skin Condition for Psoriasis and Eczema Groups.

Skin Condition	N	Mean	Minimum	Maximum	Std. Deviation
PSORIASIS	35	20.26	1	66	15.62
ECZEMA	25	20.30	0.5	50	13.60
Total	60*	20.28	0.5	66	14.69

*Information on length of time with skin condition was missing for four participants.

To establish if the differences between the two groups are significant, a between-samples t-test was completed ($t = .011$, $df = 58$ $p = NS$, one-tailed).

3.1.4 Location of Skin Disease

Objective measurement of skin severity is recognised as being difficult to obtain. Consequently, the location of skin disease was used as a distinguishing measure. As discussed earlier, this is based on the Gupta *et al.* (1988) distinction between emotionally charged areas (face, hands, wrists and genital region) and non-emotionally charged areas (legs and torso). Following consultation with dermatology staff, a category for skin lesions in the genital region was not included as it was suggested this may have a negative impact on participation in the current study. An additional category of 'all over' was included in this study to include participants with lesions in both emotionally and non-emotionally charged areas. Graph 4 and Table 5 show the frequency of participants with psoriasis and eczema in each of the three categories.

Figure 4: Bar Graph to Show Frequency of Anatomical Locations of Skin Disease in Psoriasis and Eczema Groups

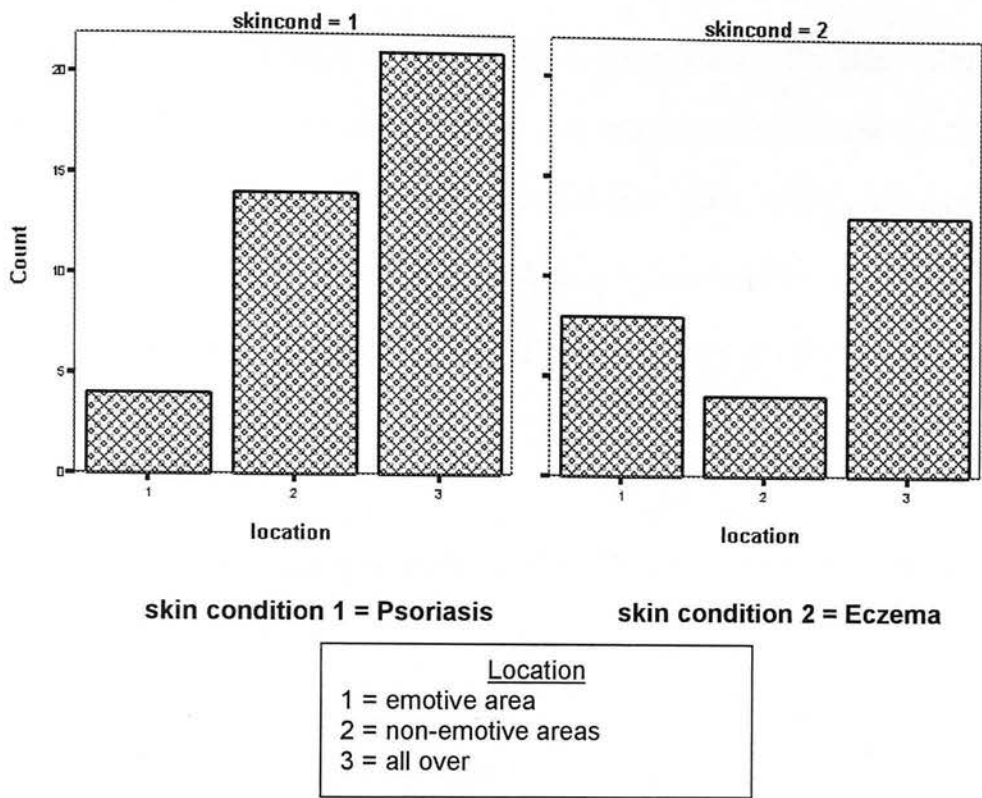


Table 5: Location of Skin Lesions for Psoriasis and Eczema Groups

Location	Skin Condition		Total
	PSORIASIS	ECZEMA	
Emotionally charged area	4	8	12 (18.75%)
Not Emotionally Charged Area	14	4	18 (28.12 %)
All over	21	13	34 (53.13%)
Total	39	25	64 (100%)

3.2 HYPOTHESES FROM THE LITERATURE

3.2.1 Hypothesis 1a

Females will report reduced quality of life in comparison to males. Research examining quality of life in individuals with skin conditions has indicted that females tend to have greater impairment in quality of life than males. Scores for males and females are compared on two quality of life factors, psychosocial and activities for both skin conditions. Between groups t-tests were used to compare scores, as illustrated in Table 6.

Table 6: T-tests between Dermatology Quality of Life Scales and Gender.

	Mean scores		t	df	Sig.(one-tailed)
	Males	Females			
Psychosocial score between males and females	32.5	45.8	-2.22	62	<.05
Activity score between males and females	31.9	45.9	-2.30	62	<.05

Results indicate that the differences between male and female on both the psychosocial and the activity based sub-scales of the Dermatology Quality of Life Scales are significant at the <.05 level.

3.2.2 Hypothesis 1b

Hypothesis 1b predicts that females will report greater stigma experience than males, as reported by the Experience of Skin Complaints (EoSC) measure. As with quality of life measures, research suggests that females report greater stigmatisation, as a consequence of their skin condition, than males. Differences between males and females were examined by comparing the overall score and scores on the five factors of the Experience of Skin Complaints measure as reported in Table 7.

Table 7: T-tests between Experience of Skin Complaints Measure and Gender.

	Mean Scores		t	df	Sig.(one-tailed)
	Males	Females			
Total Score	64.9	69.8	-1.15	62	(NS)
Self esteem	11.9	13.5	-1.53	62	(NS)
Retreat	17.9	19.3	-.861	62	(NS)
Reject	14.6	15.68	-.731	62	(NS)
Composure	13.4	14.35	-.774	62	(NS)
Conceal	7.0	7.32	-.631	62	(NS)

Results indicate that there is no significant difference between males and females, on any of the factors of the Experience of Skin Complaints measure.

3.2.3 Hypothesis 2a

Younger age is predicted to cause greater impairment in life quality for individuals with eczema and psoriasis. Researchers have suggested that individuals are most likely to be most affected by their skin condition in terms of life quality during adolescence and early adulthood. Consequently, subjects have been differentiated by

whether their skin condition started before or after they were twenty-five years old.

Table 8 compares age at onset with psychosocial and activity quality of life factors.

Table 8: T-tests between Younger and Older Age at Onset of Skin

Condition with Dermatology Quality of Life Scales

	Mean Score		t	df	Sig.(one-tailed)
	<25	>=25			
Psychosocial Quality of Life	44.1	26.0	3.06	58	<.01
Activity Quality of Life	42.6	27.5	2.45	58	<.05

* Data is missing for four individuals on age at onset of skin condition.

T-tests indicate that there is a significant difference between younger age (<25 years) and older age (>=25years) at onset of skin condition, on both factors of the Dermatology Quality of Life Scales. Results suggest that earlier age at onset of skin condition leads to greater impairment in quality of life.

Comparisons were also made between current age and length of time with a skin condition in participants scores on the Dermatology Quality of Life Scales. This analysis was carried out using Pearson's Correlations as shown in Tables 9 and 10.

Table 9: Correlations Comparing Age with Dermatology**Quality of Life**

	Age		
	N	Pearson's correlation	Sig.
Psychosocial Quality of Life	64	-.309	<.01
Activity Quality of Life	64	-.164	(NS)

Table 10: Correlations Comparing Length of Time with Skin**Condition with Dermatology Quality of Life.**

	Age		
	N	Pearson's correlation	Sig.
Psychosocial Quality of Life	60	.001	(NS)
Activity Quality of Life	60	.081	(NS)

* Data is missing for four individuals on length of time with skin condition.

On the psychosocial sub-scale of the Dermatology Quality of Life Scales (DQLS), results indicate that there is a significant relationship with current age but not length of time with a skin condition. No significant correlations were found between current age and length of time with a skin condition in relation to the activity sub-scale of the DQLS.

To establish what contribution current age, age at onset and length of time with skin condition make to the prediction of quality of life, a multiple regression analysis was conducted. A summary of the results are presented below in Table 11 and 12.

Table 11: Multiple Regression Summary for Age, Age at Onset and Length of Time with Skin Condition Associated with Dermatology Quality of Life

Dependant variable	R	Adjusted R square	F	Sig.
Psychosocial Quality of Life	.357	.081	2.72	(NS)
Activity Quality of Life	.219	.048	.943	(NS)

Table 12: Regression Analysis Coefficients for Age, Age at Onset and Length of Time with Skin Condition Associated with Dermatology Quality of Life

Dependant variable		Beta	t	Sig.
Psychosocial Quality of Life	Age	.581	.264	(NS)
	Age at Onset	-1.06	-.430	(NS)
	Length of time with	-.673	-.376	(NS)
Activity Quality of Life	Age	.532	.231	(NS)
	Age at Onset	-.824	-.321	(NS)
	Length of time with	-.465	-.249	(NS)

The results suggest that no particular variables contribute significantly to either factor on the Dermatology Quality of Life Scales.

3.2.4 Hypothesis 2b

As with quality of life measures, it is expected that younger current age and age at time of onset will predict greater stigma experience, as measured on the Experience of Skin Complaints (EoSC) questionnaire. Table 13 compares age at onset (either <25yrs or ≥ 25yrs) with total score on the EoSC and on the five factors of stigma experience.

Table 13: T-tests to Compare Younger or Older Age at Onset of Skin Condition with Experience of Skin Complaints Measure

	Mean Scores		t	df	Sig.
	<25	≥25			
Total Score	67.5	63.5	.971	58	(NS)
Self esteem	13.2	11.2	1.771	58	(NS)
Retreat	18.6	17.4	.710	58	(NS)
Rejection	15.3	14.0	.899	58	(NS)
Composure	13.5	13.8	-.230	58	(NS)
Concealment	7.1	7.1	-.082	58	(NS)

* Data is missing for four individuals on age at onset of skin condition.

No significant differences were found between younger and older age at onset and scores on Experience of Skin Complaints measure. Comparisons were also made

between current age and length of time with a skin condition using Pearson's correlations, see Tables 14 and 15.

Table 14: Correlations Comparing Age with Experience of Skin Complaints

	Age		
	N	Pearson's correlation	Sig.
Total Score	64	-.007	(NS)
Self esteem	64	-.121	(NS)
Retreat	64	.039	(NS)
Rejection	64	.026	(NS)
Composure	64	-.023	(NS)
Concealment	64	.061	(NS)

Table 15: Correlations Comparing Length of Time with Skin Condition with Experience of Skin Complaints.

	Age		
	N	Pearson's correlation	Sig.
Total Score	60	.080	(NS)
Self esteem	60	.104	(NS)
Retreat	60	.104	(NS)
Rejection	60	.141	(NS)
Composure	60	-.176	(NS)
Concealment	60	.136	(NS)

* Data is missing for four individuals on length of time with skin condition.

Results indicate that there is no significant relationship between current age and time with a skin condition on the Experience of Skin Complaints measure.

As with hypothesis 2a, to establish what contribution current age, age at onset and length of time with skin condition make to the prediction of stigma experience a multiple regression analysis was conducted. A summary of the results are presented below in Table 16 and 17.

Table 16: Multiple Regression Summary for Age, Age at Onset and Length of Time with Skin Condition associated with Stigma Experience.

Dependant variable	R	Adjusted R square	F	Sig.
Total Score Experience of Skin Complaints	.085	-.046	.137	(NS)

Table 17: Regression analysis coefficients Age, Age at Onset and Length of Time with Skin Condition Associated with Stigma Experience.

Variables	Beta	t	Sig.
Age	-.423	-.180	(NS)
Age at onset	.454	.173	(NS)
Length of time with condition	.415	.217	(NS)

3.2.5 Hypothesis 3 a.

This hypothesis explores the relationship between anatomical location of skin disease and quality of life scores on the Dermatology Life Quality Index. Subjects were divided into three categories based on their skin condition. These categories were:

1. Skin disease in emotive areas (hands, wrists and face)
2. Skin disease in non-emotive areas (legs, trunk and arms)
3. Skin disease all over the body (emotive and non-emotive areas)

Due to the variation between the group sizes for the anatomical location of skin disease, non-parametric statistical analysis was used. The Kruskal-Wallis test was used to compare the relationship between anatomical location of skin disease and quality of life.

Table 18: Kruskal-Wallis Test between Anatomical Location of Skin Disease and Dermatology Quality of Life

	Location	N	Mean Rank	H	df	Asymp. Sig.
Psychosocial Quality of Life	Emotive	12	36.92	12.51	2	<.01
	Non-emotive	18	19.36			
	All Over	34	37.9			
	Total	64				
Activity Quality of Life	Emotive	12	31.83	12.6	2	<.01
	Non-emotive	18	20.08			
	All Over	34	39.31			
	Total	64				

Results suggest that there is a significant difference between the non-emotive and the two other groups (emotive and all over) on both sub-scales of the Dermatology Quality of Life Scales.

3.2.6 Hypothesis 3 b.

As mentioned above, most of the research literature has focused on skin severity as a potential predictor of stigmatisation in individuals with skin disease. Gupta *et al.* (1998) reported that the majority of individuals reporting stigma experience had skin lesions in socially visible areas and concluded that anatomical location was a better predictor of stigmatisation than overall skin severity. This hypothesis predicts that individuals with more visible skin disease will score higher on the Experience of Skin Complaints measure. As with hypothesis 3a, the relationship between anatomical location of skin disease and stigma experience was analysed using Kruskal-Wallis Test. The results are presented in Table 19.

Table 23: Kruskal-Wallis Test between Anatomical Location of Skin**Disease and Experience of Skin Complaints**

	Location	N	Mean Rank	<i>H</i>	df	Asymp. Sig.
Total Score	Emotive	12	29.33	1.71	2	(NS)
	Non-emotive	18	29.22			
	All Over	34	35.35			
Self esteem	Emotive	12	34.33	9.23	2	.01
	Non-emotive	18	21.42			
	All Over	34	37.72			
Retreat	Emotive	12	31.63	3.06	2	(NS)
	Non-emotive	18	32.58			
	All Over	34	32.76			
Rejection	Emotive	12	25.17	.034	2	(NS)
	Non-emotive	18	37.56			
	All Over	34	32.41			
Composure	Emotive	12	33.67	3.21	2	(NS)
	Non-emotive	18	29.31			
	All Over	34	33.78			
Concealment	Emotive	12	33.67	.765	2	(NS)
	Non-emotive	18	29.31			
	All Over	34	33.78			

Overall, the results do not support the hypothesis that greater visibility of skin condition leads to greater experience of stigma. The only significant result obtained indicates that significant difference on the self-esteem sub-scale.

3.2.7 Hypothesis 4

The research literature, examining the use of coping mechanisms in stressful situations, has tended to suggest that those who adopt any active problem solving strategy will show less psychological impairment. This hypothesis is examined by simple correlations between scores on the COPE and individual psychosocial score on the Dermatology Quality of Life Scales. The data is treated as ordinal and analysed using Kendall's Tau Correlation Coefficient.

Table 20: Correlations between Psychosocial Quality of Life and Specific Coping Strategies*

	N	Kendall's Tau-b	Significance
Psychosocial Quality of Life			
Active Coping	64	-.075	(NS)
Planning	64	.012	(NS)
Instrumental Social Support	64	-.032	(NS)
Emotional Social Support	64	.006	(NS)
Suppression	64	.029	(NS)
Religion	64	-.01	(NS)
Positive Reinterpretation	64	-.66	(NS)
Restraint	64	.111	(NS)
Acceptance	64	-.183	(NS)
Focus on and Vent Emotions	64	.454	<.05
Denial	64	.129	(NS)
Mental Disengagement	64	.334	<.05
Behavioural Disengagement	64	.165	(NS)
Alcohol and Drugs	64	.209	(NS)
Humour	64	-.155	(NS)

* Results, in the above table, have been corrected for multiple tests of significance by dividing the .05 level of significance by the number of correlations carried out.

Table 20 shows that there are significant correlations at the 0.05 level between psychosocial quality of life and two coping strategies; focusing on and venting of emotions, and mental disengagement.

3.2.7 Hypothesis 5

Being stigmatised, due to an individuals skin condition, is frequently mentioned in dermatology quality of life literature as one of the strongest predictors of impaired quality of life. Consequently, in this hypothesis, it is predicted that both psychosocial and activity-based quality of life measures will correlate with scores obtained on a measure of stigma experience (Experience of Skin Complaints). As in hypothesis 4, the data is treated as ordinal and analysed using Kendall's Tau Correlation Coefficient. Results are shown in Tables 21 and 22.

Table 21: Correlations between Psychosocial Quality of Life and Stigma Experience*

	N	Kendall's Tau-b	Sig.
Psychosocial Quality of Life			
Total Stigma Experience	64	.434	<.05
Self-esteem	64	.488	<.05
Retreat	64	.391	<.05
Rejection	64	.200	(NS)
Composure	64	.300	<.05
Concealment	64	.139	(NS)

* Results have been corrected for multiple tests of significance by dividing the .05 level of significance by the number of correlations carried out.

Table 22: Correlations between Activity Based Quality of Life and Stigma Experience.*

	N	Kendall's Tau-b	Sig. (2-tailed)
Activity Quality of Life			
Total Stigma Experience	64	.451	<.05
Self-esteem	64	.429	<.05
Retreat	64	.471	<.05
Rejection	64	.232	(NS)
Composure	64	.242	(NS)
Concealment	64	.147	(NS)

* Results have been corrected for multiple tests of significance by dividing the .05 level of significance by the number of correlations carried out.

Results indicate that both psychosocial and activity-based quality of life scores correlate with total stigma experience and two factors of the Experience of Skin Complaints measure; self-esteem and retreat. The sub-scale for composure correlates with the psychosocial sub-scale but not the activity sub-scale. The retreat and concealment sub-scales on the Experience of Skin Complaints measure does not correlate with either factor of the Dermatology Quality of Life Scales.

3.3 EXPERIMENTAL HYPOTHESIS

3.3.1 Hypothesis 6 a

In the current research literature, psoriasis and eczema are usually described together and few studies examining quality of life differentiate between them. Studies on dermatological quality of life often group psoriasis and eczema, along with acne, as the skin conditions in which the greatest degree of impairment in quality of life is reported. Consequently, in this study, it was expected that there would be no significant difference in the impairment of life quality as measured by the Dermatology Quality of Life Scales between the psoriasis and eczema groups in this study. To examine this further a between groups t-test was carried out, as reported in Table 23.

Table 23: T-tests between Dermatology Quality of Life in Psoriasis**Group and Eczema Groups**

	Mean Scores		t	df	Sig.
	Psoriasis	Eczema			
Psychosocial score between psoriasis and eczema groups	40.7	37.7	.472	62	(NS)
Activity score between psoriasis and eczema groups	41.3	36.3	.790	62	(NS)

Results indicate that there is no significant difference between Dermatology Quality of Life Scales scores for participants with psoriasis and eczema.

3.3.2 Hypothesis 6 b

Most of the current research exploring stigmatisation, as a consequence of skin disease, has focused on individuals with psoriasis although it is assumed that individuals with eczema suffer similar experiences. Despite claims of the Experience of Skin Complaints measure to be applicable to all skin diseases, it was only tested on individuals with psoriasis. To examine if there was a difference in experience of stigma, as reported in this study, between groups t-tests were carried out, examining total stigma experience and individual factors for psoriasis and eczema subjects, as illustrated in Table 24.

Table 24: T-tests between Experience of Skin Complaints in the Psoriasis and Eczema Groups.*

	Mean Scores		t	df	Sig.
	Psoriasis	Eczema			
Total					
Stigmatisation	72.4	60.0	3.05	62	<.05
Self-esteem	13.2	12.1	1.02	62	(NS)
Retreat	20.0	16.5	2.17	62	(NS)
Rejection	16.1	13.7	1.56	62	(NS)
Composure	15.7	11.0	4.22	62	<.05
Concealment	7.7	6.4	2.53	62	(NS)

* Results have been corrected for multiple tests of significance by dividing the .05 level of significance by the number of t-tests carried out.

Results indicate that there is, in fact, significant differences between participants with psoriasis and eczema on total scores on the Experience of Skin Complaints (EoSC) measure. Of the sub-scales of the EoSC only the factor for composure shows a significant result between psoriasis and eczema participants.

3.3.3 Hypothesis 7

Ginsburg and Link (1993) suggested that an understanding is required of the coping mechanisms employed by individuals who feel stigmatised by their skin condition. This hypothesis predicts that stigma experience is modulated by coping mechanisms. To examine which coping mechanisms are predictive of stigma experience, a stepwise multiple regression analysis was conducted. Two factors on the COPE (alcohol/drugs and humour) were excluded from the regression analysis as these

factors were not included in the initial design and validation of the COPE questionnaire. Results are indicated in Table 25 and 26.

**Table 25: Multiple Regression Summary for Coping Mechanisms
Associated with Stigma Experience.**

Dependant variable	R	Adjusted R square	F	Sig.
Total stigma score	.400*	.147	11.83	.001

**Predictors:* Behavioural Disengagement

Stepwise Criteria: probability of F to enter $\leq .05$ and probability of F to remove $\geq .10$. Variables excluded = active coping, planning, seeking instrumental social support, seeking emotional social support, suppression, religion, reinterpretation, restraint, acceptance, focus on and venting of emotions, denial and mental disengagement.

**Table 26: Regression Analysis Coefficients for Coping Mechanisms
Associated with Stigma Experience**

Variables	Beta	t	Sig.
Behavioural Disengagement	.400	3.44	.001

Results from the multiple regression analysis suggest that behavioural disengagement is the most predictive of total stigmatisation score.

Due to the limited sample size in this study, multiple regression analysis of coping mechanisms associated with stigma experience for the psoriasis and eczema groups is not possible. Therefore, correlations between total scores on the Experience of Skin Complaints measure and COPE for each of the two groups were conducted using Kendall's Tau correlation coefficient. These correlations are reported in Tables 27 and 28.

Table 27: Correlations between Total Stigma Experience and Coping Strategies for Psoriasis Group.*

	N	Kendall's Tau-b	Significance
Total stigma experience			
Active Coping	39	-.06	(NS)
Planning	39	.01	(NS)
Instrumental Social Support	39	-.091	(NS)
Emotional Social Support	39	.085	(NS)
Suppression	39	.077	(NS)
Religion	39	.183	(NS)
Positive Reinterpretation	39	.033	(NS)
Restraint	39	.172	(NS)
Acceptance	39	.023	(NS)
Focus on and Vent Emotions	39	.353	(NS)
Denial	39	.188	(NS)
Mental Disengagement	39	.341	(NS)
Behavioural Disengagement	39	.260	(NS)
Alcohol and Drugs	39	.198	(NS)
Humour	39	.080	(NS)

* Results have been corrected for multiple tests of significance by dividing the .05 level of significance by the number of correlations carried out.

Table 28: Correlations between Total Stigma Experience and Coping**Strategies for Eczema group.***

	N	Kendall's Tau-b	Significance
Total stigma experience			
Active Coping	25	-.122	(NS)
Planning	25	.096	(NS)
Instrumental Social Support	25	-.092	(NS)
Emotional Social Support	25	.032	(NS)
Suppression	25	.035	(NS)
Religion	25	-.262	(NS)
Positive Reinterpretation	25	-.175	(NS)
Restraint	25	.025	(NS)
Acceptance	25	-.149	(NS)
Focus on and Vent Emotions	25	.066	(NS)
Denial	25	.268	(NS)
Mental Disengagement	25	.164	(NS)
Behavioural Disengagement	25	.158	(NS)
Alcohol and Drugs	25	.528	<.05
Humour	25	-.088	(NS)

* Results have been corrected for multiple tests of significance by dividing the .05 level of significance by the number of correlations carried out.

Results indicate that there is no major difference between the coping strategies used by psoriasis participants, in comparison to eczema participants, in the modulation of stigma experience. The only significant result is that eczema participants are more likely to use alcohol and drugs as a means of coping with stigma.

3.4 QUALITATIVE ANALYSIS

3.4.1 Participants

Fifty of the individuals, initially approached in the main study, were asked if they wished to take part in a short interview after completion of the questionnaire measures. Of those who completed the questionnaires, twenty individuals offered to attend a short interview. Of these, ten either failed to attend the appointment arranged or cancelled due to unsuitable times or other commitments. Consequently, ten individuals were interviewed for this study. On completion of these ten interviews, it was decided not to interview any further participants as similar themes were emerging from the information gathered. Participants, who were inpatients, were mainly interviewed during their ward stay. One patient was interviewed in her own home following discharge. All outpatient subjects were interviewed in the Clinical Psychology Department of the hospital, where they were currently receiving treatment. Unfortunately, due to interference on the tape, one of the interviews could not be transcribed. Therefore, nine participants are included in this part of the study. A summary of the participants is given below in Table 29.

Table 29: Descriptive Information of Participants who Attended the Semi-Structured Interviews

Subject	Gender	Age	Current Treatment	Skin Condition	Age at Onset
1	Male	70	Inpatient	Psoriasis	59
2	Male	46	Outpatient	Psoriasis	9
3	Male	45	Outpatient	Psoriasis	27
4	Female	45	Inpatient	Eczema	14
5	Male	70	Inpatient	Eczema	50
6	Female	17	Inpatient	Eczema	0
7	Female	53	Outpatient	Psoriasis	50
8	Female	37	Inpatient	Psoriasis	20
9	Male	24	Outpatient	Eczema	15

3.4.2 Researcher Bias

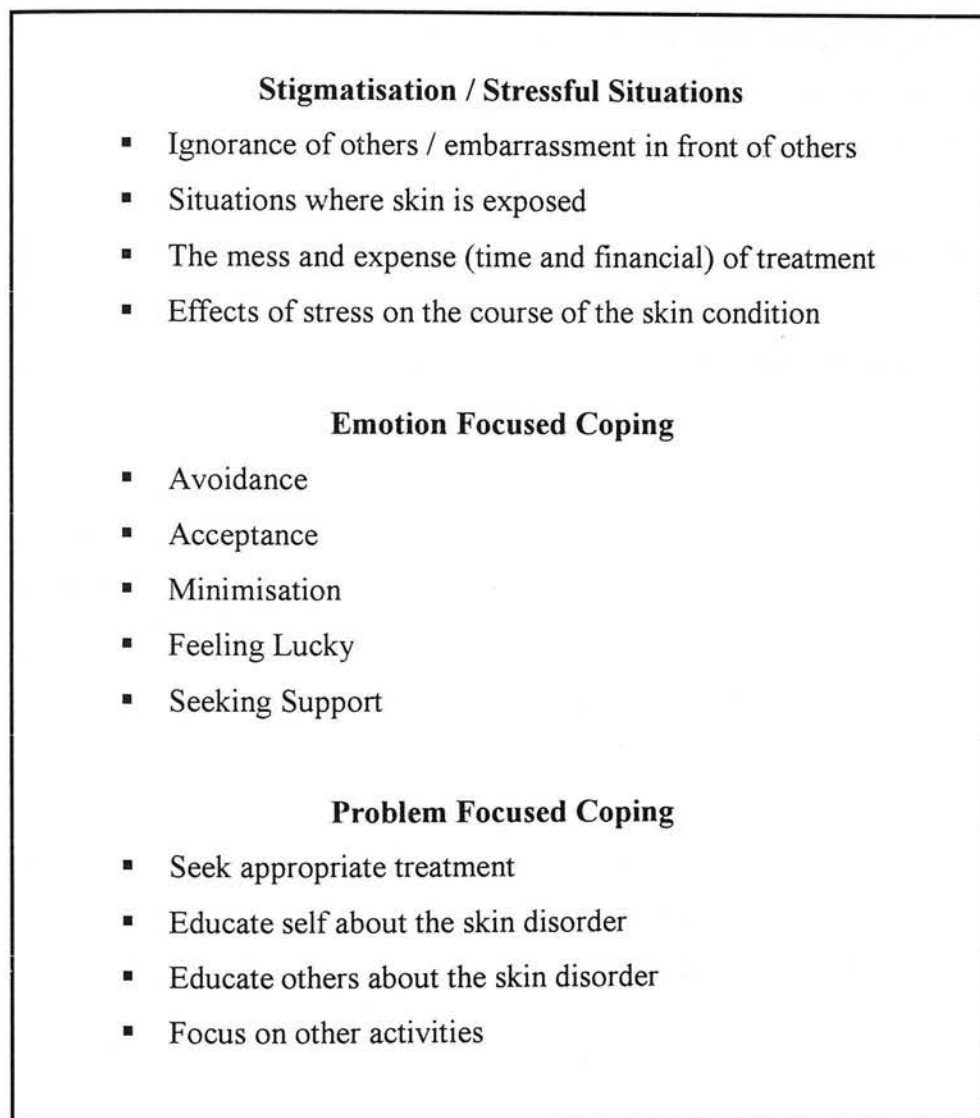
As in all qualitative analysis, it is important to outline researcher bias before analysis of the data. In this study, researcher bias was directed towards skin conditions, their course and consequences, having a clear influence on psychological wellbeing. In addition, the bias that psychological stress can effect the course of a skin condition was also evident.

3.4.3 Data Analysis

Data was analysed using grounded theory techniques to identify specific themes taken from the existing literature on coping and stigmatisation. The main themes explored were taken from the research of Metz and Jemec (1996), and Taylor and

Buckwalter (1988). The main themes identified, which corresponded to the current literature, were split into three broad categories as outlined below in Figure 1.

Figure 5: Main Categories Identified from Subject Interviews which Correspond to Current Literature



Examples for each of the main categories are given below. For each theme, subjects, who were coded as having mentioned the particular theme, are identified in brackets.

**Table 30: Examples from Transcripts Relating to Stigmatisation /
Stressful Situations**

<i>Stigmatisation / Stressful Situations</i>	<i>Examples</i>
Ignorance of others / Embarrassment	<p>“You see people looking at you funnily sometimes and perhaps wondering what on earth is wrong with you.”</p> <p>“A family friend thought my psoriasis was contagious. She used to keep a cup and plate separate for me to use. She thought if she used them she would catch it.” (1,2,6,7,8,9)</p>
Situations where skin is exposed	<p>“When I’m on holiday I’ll cover up to avoid people looking at my skin.”</p> <p>“I hate wearing dark clothes in case the flakes of skin show up” (2,3,4,6,7,8,9)</p>
Mess and expense of treatment	<p>“Everything gets greasy and basically has to be laundered separately”</p> <p>“It is difficult to find the time to put on the medications and it is impossible to put the treatments on your back yourself.” (2,4,5,9)</p>
Effect of stress	<p>“If I am upset about anything I know that it will make it worse”</p> <p>“I’ve been told that stress makes it worse but I haven’t found that it does get any worse when I am stressed” (4,7,8,9)</p>

**Table 31: Examples from Transcripts Relating to Emotion Focused
Coping**

<i>Emotion Focused</i>	<i>Examples</i>
Avoidance	<p>“The most frustrating thing is that when it is all over your body you tend to shy away from relationships...sexual relationships.”</p> <p>“I used to love swimming but there is no way I would go now.”</p> <p>“I have to admit I do go out and drink a lot sometimes, to take my mind off it.” (2,4,5,6,8,9)</p>
Acceptance	<p>“You have to get out and get on with your life the best you can.”</p> <p>“I’ve had it for so long now I think I have come to terms with it”</p> <p>“If I had filled in your questionnaires fifteen years ago the answers would have been quite different, no I think I’ve just come to accept it.” (1,2,3,6,7,9)</p>
Minimisation	<p>“I’ve seen how bad other people can be and I think thank God I’m not that bad”</p> <p>“You don’t die from it a lot worse things can happen”</p> <p>“You are almost a fraud in here (hospital) because you are not ill as such.” (2,5,7,9)</p>
Feel Lucky	<p>“I’m lucky that I don’t have it on my face...I would say it must be 100 times worse for a woman.”</p> <p>“I’ve been fortunate that I’ve never had it on my face, it might have been different if it had been on my face.” (2,3,4,5,7)</p>
Seek Support	<p>“If you spot someone with psoriasis...it is like you are kindred spirits and have a good natter about it.”</p> <p>“It is nice to speak to someone (hospital staff) who can understand what is the matter with you. They can appreciate that you are itching like hell and want something done about it.” (2,5,7)</p>

Table 32: Examples from Transcripts Relating to Problem Focused Coping

<i>Problem Focused</i>	<i>Examples</i>
Seek appropriate treatment	“I’m used to using the creams and things because I know that I can keep it under control.” “I’ve now got an open appointment so I can get it seen as soon as it flares up.” (3,4,5)
Educate self	“I know myself that if I do something (referring to triggers to flare-ups) it is on my own head, it is me that has to suffer for it.” (1,6)
Educate Others	“I think they should talk about it more in schools and let them know what some folk have got to put up with.” (1,2)
Focus on other activities	“I’ve always got something to occupy myself with and take my mind off my psoriasis” (1,5)

Not all the information gathered during the interviews neatly fitted into the above categories. Consequently, four further categories were identified these are described in Figure 6.

Figure 6: Themes Generated from Subject Interviews

- 1. Frustration at the unpredictability of the course of skin disease.**
 - 2. Self-esteem**
 - 3. Effect on significant others**
 - 4. Positive cognitions**

Examples of participant responses identified as belonging to these themes are indicated below.

Table 33: Examples of Transcripts Relating to Participant Generated Themes.

<i>Additional themes</i>	<i>Examples</i>
Frustration at unpredictability	<p>"I see myself getting on, then another eruption happens which puts me back to square one"</p> <p>"Sometimes it is quite bad and I am doing all the right things and it doesn't clear up, that can be quite frustrating."</p> <p>"You feel wonderful when your skin clears, really clean. Then gradually you see little pinpricks coming back, that is really frustrating"</p> <p>"I have this fear that once this treatment is finished it is going to come back. I don't think I could handle that." (1,4,6,7,8,9)</p>
Self-esteem	<p>"It makes you feel like you are really dirty. You feel awful and you get so embarrassed."</p> <p>"Having it all these years, you sort of withdraw into yourself a bit."</p> <p>"I became quite anti-social for a time (when skin condition first developed)." (1,6,7,9)</p>
Effect on significant others	<p>"I think it can really affect the family. It is like they have it as well."</p> <p>"I think I have been lucky my husband has accepted it. I don't know if I would have been as sympathetic if he had it." (2,3,7,8,9)</p>
Positive cognitions	<p>"You've just got to ignore other people it is not worth getting worked up about."</p> <p>"The staff say think positive...I've been doing that all the time if I didn't I would be dead." (2,6,7)</p>

3.4.3 Summary of Qualitative Data

From the information given in the interviews, it is evident in this sample group that having psoriasis or eczema is something that they have learned to cope with. For others, having one of these skin conditions is a major frustration in their lives. In particular, frustration at the unpredictability of the course of the disease, avoidance of situations when the skin is exposed, and ignorance of others about skin conditions, are the most frequently reported themes in this study.

3.5 SUMMARY OF RESULTS

3.6.1 Comparisons with Previous Research

The results of this study overall replicate earlier findings relating to gender, age and location of skin disease in quality of life and stigmatisation in dermatology Patients. Females appear to have impaired quality of life but similar stigma experience in comparison with males. Age appears to be a contributory factor in quality of life, only when participants are separated in to older and younger age groups. In relation to stigmatisation, no age factors are significant to stigma experience. There is only a significant difference between 'emotive' anatomical locations and 'non-emotive areas' on psychosocial quality of life, although subject numbers in these divisions are small. In correlations between psychosocial quality of life and coping mechanisms not all the items which correlate highly are active problem solving strategies as predicted. Finally, with the exception of concealment, stigma experience correlates with both psychosocial and activity based quality of life.

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3.6.2 Differences between Psoriasis and Eczema

As expected there are no differences between patients with eczema and psoriasis for quality of life. However, there appears to be a significant difference between stigmatisation experience in the two skin conditions.

3.6.3 Links between Coping Mechanisms and Stigma Experience

Multiple Regression analysis, examining stigma experience with coping mechanisms suggests that behavioural disengagement is the coping strategy most predictive of stigma experience. Only one coping strategy correlates with stigma experience for the eczema groups. There are no significant correlations for the psoriasis group.

3.6.4 Qualitative Analysis

A number of themes are identified from current research literature and generated from participant interviews. A surprisingly broad range of themes has been identified, given the general questions asked during the interviews. From this small sample group, the major themes which were identified were; frustration at the unpredictability of skin disease, the ignorance of others and the need for avoidance of stigmatisation by concealment of skin disease or withdrawal from activities.

CHAPTER 4 – DISCUSSION

4.1 GENERAL SUMMARY OF RESEARCH

Ginsburg and Link (1989, 1993) suggested that their research on stigmatisation in psoriasis patients would benefit from exploration of the coping techniques used by psoriasis patients. The principal aim of the current study was to explore the relationship between stigmatisation and coping style. As there has been no research to date exploring these issues in individuals with eczema, subjects with this skin condition were included in the study. Stigmatisation has often been referred to as a factor in quality of life of dermatology patients. To allow greater comparison with previous research, the relationship between quality of life, stigma experience and coping style in individuals with psoriasis and eczema was also explored. As an adjunct to this study, nine volunteers attended for interview to give their personal experiences in relation to quality of life, stigma experience and how they cope with their skin condition.

4.2 GENERAL FINDINGS

The present study is comparable with previous research examining quality of life and stigmatisation in dermatology patients in relation to subject numbers, gender and age mix. The response rate for participants (70.3 per cent) is quite high for a questionnaire- based design. The rate is exceptionally high given the relatively lengthy measures used and that the majority of participants completed the measures in their own time and returned them at their next appointment. Most of the current

research examining stigma experience and quality of life in dermatology patients, has recruited consecutive inpatients and/or outpatients and response rates are not reported (Gupta *et al.* 1988; Ginsburg and Link, 1993). As mentioned in the introduction, there are few studies which directly compare the differences between individuals with psoriasis and eczema. Results in the current study suggest that the main difference between the psoriasis and eczema groups were the mean current age and mean age at onset of the skin condition, with the eczema group being significantly younger than the psoriasis group. These differences are attributable to different mean ages at onset for the two skin conditions. Onset of eczema mainly occurs in childhood (Herd *et al.*, 1997), while psoriasis has a bimodal distribution with the first peak of onset during late adolescence and early adulthood and a second peak in late middle age (Klaber, 1992). Using the definitions for anatomical location of skin disease devised by Gupta *et al.* (1998), there appears to be some difference between the numbers of psoriasis and eczema sufferers with skin disease in non-emotive areas of their body, such as the back, chest and legs. More eczema sufferers report skin disease in emotive areas such as the face. However, as the majority of participants indicated that their skin disease was all over their bodies, it is difficult to establish if there is a statistically significant difference between participants with psoriasis and eczema.

Interestingly, many participants welcomed the opportunity to discuss difficulties they have had with their skin condition, especially the opportunity to discuss their difficulties and frustrations at having a skin condition. As a whole, the dermatology patients were very enthusiastic about participating in this study and frequently

commented that they hoped such research would help others avoid the difficulties they had faced. In addition, many of the older participants expressed that their responses would have been much different when they were younger. They explained that they had now accepted their skin condition and had learned to cope with it.

4.3 HYPOTHESES FROM THE LITERATURE

4.3.1 Hypotheses 1a and 1b – Gender differences will be evident in quality of life and stigma experience

It was predicted that there would be a significant difference between scores obtained by males and females on the Dermatology Quality of Life Scales (DQLS). Results confirmed this hypothesis, with significant results reported on both sub-scales of the DQLS with females reporting greater impairment in quality of life. In development of the DQLS, Morgan *et al.* (1997) reported that the measure corresponded with previous research in reporting greater psychosocial impact of skin conditions in females than males. One of the earliest papers to review this gender difference was by Roenigk and Roenigk (1978), in a study of individuals with psoriasis. On all measures used in this study, females reported greater impairment than males, although the statistical significance was limited. The results relating to outdoor, leisure and social activities, which are similar to the activity sub-scale in this study, were not found to be significant. Inclusion of the eczema group in the current study makes such a direct comparison difficult. Other research has produced contrasting views. Fortune *et al.* (1987), in a study of quality of life in psoriasis patients, found

no gender differences in any of the quality of life measures used in the study. A similar study by Linnet and Jemec (1999), in individuals with atopic dermatitis, found no gender differences on the Dermatology Life Quality Index (Finlay and Khan, 1994). With such varied results, further research using larger sample sizes than in the studies mentioned is required to establish if there are differences between males and females in quality of life issues associated with having a skin condition.

The second prediction, made in relation to this hypothesis, was that females would report greater stigma experience than males. For total score on the experience of Skin Complaints (EoSC) measure, and all sub-scales of the measure, no significant differences were found between males and females in this study. Unfortunately, none of the research papers examining stigmatisation in individuals with skin conditions have compared the results given by males and females. Others have anecdotally suggested that stressful situations, such as being stigmatised, may be greater for women, when a cosmetically disfiguring condition can result in social disapproval (Jowett and Ryan, 1985). In a study examining illness-related stress, including stigmatisation in individuals with psoriasis, Fortune *et al.* (1997) concluded that women were more likely to experience stress in stigmatising situations that involved rejection. In the current study there is no significant difference for males and females on the rejection factor of the EoSC measure. From the qualitative data collected in this study, it was interesting that several male subjects commented that they thought “it must be 100 times worse for a woman”, but this was not reflected in the quantitative analysis with the Experience of Skin Complaints measure. These non-significant results may reflect the greater emphasis

in the EoSC measure on personal opinion of stigmatisation in skin conditions, rather than personal experience. Further research in this area could perhaps clarify differences, if any, in actual experiences of stigmatisation between males and females.

4.3.2 Hypotheses 2a and 2b – Younger age groups will experience greater impairment in quality of life and greater stigma experience.

It was predicted that the age of the participant, their age at the onset of the skin condition and length of time with skin conditions, would impact on quality of life and reported stigma experience. In examining the effect of age at onset on quality of life, subjects were divided into two groups, a younger group (<25 years) and an older group (≥ 25 years). Results indicated that there was a significant difference between the younger and older groups on both the psychosocial and activity subscales of the Dermatology Quality of Life Scales (DQLS) measure. Although, the groups varied in size, (39 in the younger group and 21 in the older group), this reflects the general pattern that the majority of individuals will develop a skin condition before age 30 (Folks and Kinney, 1992). In the development of the DQLS, Morgan *et al.* (1997) reported that younger age was significantly associated with a higher psychosocial score. Unfortunately they do not report if there was any significant association with a higher activity score. Other authors report significant results between the younger and older groups on measures of psychosocial quality of life (Fortune *et al.*, 1997a). The significant correlation between current age and psychosocial sub-scale of the DQLS add further support to the hypothesis. Non-significant results were found in comparing the relationship between the length of

time with skin condition for both factors of the DQLS. In a study of quality of life in psoriasis patients, Fortune *et al.*, (1997b) reported similar findings, indicating that the duration of skin disease was unrelated to any area of quality of life. In a multiple regression analysis, results indicated that none of the variables relating to age, ages at onset or length of time skin condition, were predictive of dermatology quality of life.

Similar comparisons were made between younger and older groups at age of onset in relation to the Experience of Skin Complaints measure (EoSC). Results showed there were no significant differences between the total score or any factors on the EoSC in the younger and older groups. These results contrast to those reported by Ginsburg and Link (1989). The authors reported that being older at onset of psoriasis protects individuals against anticipating rejection and being sensitive to the opinion of others, which is associated with stigmatisation. Non-significant results were also found in the current study, in examining the relationship between current age and stigma experience. In comparing length of time with skin condition and stigma experience, no significant relationships were found. These results contrast with previous research where longer duration of having the skin condition was associated with less guilt and shame, and less secretiveness (Ginsburg and Link, 1989). The experiences reflected in the qualitative analysis may correspond more to Ginsburg and Link's (1989) findings. Three of the older individuals interviewed suggested that their responses would have been quite different when they were younger, and as they had grown older they had been more accepting of their skin condition. As with quality of life, multiple regression analysis indicated that none of the variables

relating to age, age at onset or length of time skin condition, were predictive of experience of stigma.

In this study, there appears to be some effect of current age and age at onset on dermatology quality of life, but not stigma experience. With a significant difference in current age at age at onset between the psoriasis and eczema groups, caution is required in interpreting the results. Analysis of the two groups separately may have yielded quite different results.

4.3.3 Hypothesis 3a and 3b - Greater visibility of skin disease will lead to poorer quality of life and greater stigma experience

Research examining the importance of anatomical location of skin disease has been mixed. The majority of the research literature has tended to focus on severity of skin condition in examining differences on quality of life and stigma experience. Fortune *et al.* (1998) suggest that there is growing anecdotal evidence that clinical severity is not a good indicator of quality of life or psychosocial wellbeing. To examine this further, subjects in this study were categorised on the basis of the anatomical location of their skin condition. The categories used are based around Gupta *et al.* (1998) definition of emotional ('emotive') and non-emotional ('non-emotive') areas. A third category, 'all over', including both emotional and non-emotional areas of skin disease was included in this study. Fortune *et al.*, (1997b) describe similar definitions that correspond to socially visible or non-socially visible anatomical locations.

Results indicated that there is a significant difference on both the psychosocial and activity sub-scales of the Dermatology Quality of Life Scales (DQLS). The results suggest that individuals with skin lesions in 'non-emotive' areas, compared to 'emotive' or 'all over', report less psychosocial impairment. These findings compare favourably with previous research that reports social visibility of skin lesions to be associated with self-report of poorer physical health and to a lesser extent mental health (Fortune *et al.*, 1997b).

Similar analysis was conducted to examine the relationship between anatomical location of skin disease and experience of stigma. The only significant result reported is on the factor of the Experience of Skin Complaints measure (EoSC) related to self-esteem. Individuals with 'non-emotive' areas of skin disease score significantly lower than the 'emotive' and 'all over' groups. Items on the self-esteem scale relate to issues such as feelings of worthlessness and feeling unclean. Perhaps those with skin conditions, that cannot be hidden from the view of others, are more likely to experience such feelings. Gupta *et al.* (1998), in a study exploring perceived deprivation of social touch in individuals with psoriasis, reported that all subjects who reported a stigma experience had at least one body region affected that was socially visible. An earlier study by the same research group, Gupta *et al.*, (1989) reported disease-related stress to be significantly correlated in psoriasis patients with lesions in 'emotionally-charged' body regions. Information collected in the qualitative analysis also relates to this hypothesis. Five of the subjects interviewed indicated that they felt lucky that they had never had their skin condition on their faces and that "it might have been different if I had it on my face".

Interestingly, the four other subjects who were interviewed all had skin lesions on their face. One of these individuals commented, “if it was anywhere else on my body I could handle that, but when it is on my face or hands, it’s the immediate contact that other people can see”.

Overall, the numbers in the ‘emotive’ and ‘non-emotive’ groups are small. As the descriptions for ‘emotive’ and non-emotive’ areas have altered from the Gupta *et al.* (1989) paper it is impossible to add support to their findings. The results from the qualitative analysis however appear to support Gupta *et al.*’s concept that those with lesions in emotive areas experience greater difficulties. Future studies with a larger subject groups and clearer definitions of what constitutes ‘emotive’ and ‘non-emotive’ areas may yield more conclusive answers.

4.3.4 Hypothesis 4 – Levels of psychosocial distress will be lower in individuals who adopt active problem solving approaches to coping

In this study, active problem solving approaches to coping were measured using the COPE. To establish if there is a relationship between active coping and greater psychosocial quality of life, correlations were conducted between sub-scales of the COPE and the psychosocial sub-scale of the Dermatology Quality of Life Scales (DQLS). As mentioned in the introduction, Carver *et al.* (1989) suggest that active coping is similar to the core of Lazarus and Folkman’s (1984) problem-focused coping, with the addition of several factors. These include ‘planning’, ‘suppression of competing activities’, ‘restraint coping’, and ‘seeking social support for

instrumental reasons'. In this study, none of these factors showed a significant correlation with psychosocial quality of life. As the COPE was designed to examine coping strategies used in stressful situations, it is perhaps not as applicable to the long-term stresses faced by individuals with chronic illness.

As Schüssler (1992) suggests, the course of chronic disease is not only determined by biomedical or genetic factors but also by the way, the patient deals with his or her illness. Hence, Patient's coping capabilities mediate between the disease and its psychosocial effects. Psychological problems mainly arise in patients with insufficient coping capabilities (Metz and Jemec, 1996). Many authors have suggested that emotion-focused coping frequently occurs in individuals who do not accept their illness or feel unable to control it. In contrast, those who use problem-focused approaches have a better outcome (Felton *et al.*, 1984; Aldwin and Revenson, 1987; and Schüssler, 1992). Certainly, in this study, there appears to be a relationship between emotion-focused coping and greater psychosocial impairment. The only significant relationships found are on two factors, focusing on and venting emotions and mental disengagement. This suggests that participants who use these dysfunctional coping mechanisms expressed greater psychological impairment as measured by the DQLS. Overall, caution must be observed in interpretation of these results, as the psychosocial sub-scale of the DQLS, although validated, is a rather broad means of measuring psychological impairment. To allow comparison with the extensive literature examining anxiety and depression, in psoriasis and eczema, use of standardised anxiety and depression measures could have been used. Future studies could perhaps use these standardised measures to indicate relationship with

coping strategies. It may also be advantageous to compare coping with general every-day stresses with the situational stresses related to having a chronic skin condition. The COPE would be an ideal measure for this as it allows comparison between dispositional and situational coping.

4.3.5 Hypothesis 5 - Levels of psychosocial distress will be higher in individuals reporting greater stigma experience.

As predicted, the results indicate that there is a significant relationship between both psychosocial and activity-based quality of life. In particular, there are significant correlations between total score on the Experience of Skin Complaints (EoSC) measure and both factors on the Dermatology Quality of Life Scales. The concealment factor does not correlate with either sub-scale of the Dermatology Quality of Life Scales (DQLS). This result is surprising, as concealment refers to tendencies to keep the skin condition a secret and hiding the diagnosis from others, which would be expected to have a considerable effect on quality of life. Ginsburg and Link (1993) identify secretiveness as one of the main outcomes of stigma experience. Qualitative analysis of the semi-structured interviews suggested that concealment of the skin condition through avoidance of the skin being exposed, through avoidance of activities, and through wearing concealing clothing are frequent responses. This non-significant result could in part be explained by methodological issues associated with the EoSC measure. The factor concealment consists of only four items, whereas other factors on the scale consist of between six and nine items. In addition, modification of the scoring scale, by including a midpoint of 'not sure', may have restricted scoring on this smaller factor. Both

retreat and self-esteem significantly correlate with both sub-scales of the DQLS. The retreat factor relates to outer appearance and situations that lead to avoidance of stigmatisation. It may be that this factor is more representative of Ginsburg and Link's factor of secretiveness. The rejection factor, which was not significant for both psychosocial and activity based quality of life, taps items relating to anticipated or expected rejection from others. This result contradicts the Ginsburg and Link (1993) study, when they reported high correlation between anticipation of rejection and quality of life issues, such as problems at home and work and avoidance of public places, as a consequence of having a skin disease. Although their study focused on acts of outward rejection, both Ginsburg and Link (1993) and Gupta *et al.* (1998) acknowledge that subtle rejection can be just as detrimental to an individual's quality of life. From the semi-structured interviews, it was noted that avoidance of situations, where the individual may feel stigmatised by their skin condition, was one of the most frequently reported items. These experiences were evident amongst some participants in the main study as well. One female with psoriasis noted her feelings about being stigmatised by her skin condition. Following completion of the EoSC measure, she wrote;

"My skin condition is hereditary, I accept that, but at the same time I feel why me, when there are three siblings and I am the only one to have it. At the same time I would not wish it on any of my sisters. Psoriasis is, and always has been. the bane of my life. Right from childhood through to adulthood I have been ridiculed, avoided, shunned, laughed at, right down to people openly going up to your face. I hate it and I feel for my husband who does

not have psoriasis but still has to suffer because of it. I do pray not for myself but for my children that they do not inherit that!”

These results indicate that there is a significant link between stigmatisation and impaired quality of life in individuals with psoriasis and eczema.

4.4 EXPERIMENTAL HYPOTHESES

4.4.1 Hypotheses 6a and 6b – Psoriasis and Eczema Patients will report similar levels of stigma experience and quality of life

It was predicted that there would be no difference between psoriasis and eczema patients in dermatological measures of quality of life. Much of the current research examines eczema and psoriasis separately or groups them together with other skin conditions. There has been no research to date exclusively comparing quality of life in the two conditions. However, the course, treatment and problems faced by psoriasis and eczema sufferers are often seen as very similar, thus prompting the lack of distinction in quality of life research. In this study, it was reported that there is no significant difference between psoriasis and eczema subjects on both factors of the Dermatology Quality of Life Scales. Interestingly in the development of the Dermatology Quality of Life Scales, Morgan *et al.* (1997) report a difference in mean scores between Psoriasis and Eczema subjects on both factors of the questionnaire. Unfortunately, they do not report if these differences are statistically significant.

However, the small numbers of psoriasis patients ($n=23$) and eczema patients ($n=18$) in the Morgan *et al.* (1997) study may account for such differences.

Although, the majority of research exploring stigmatisation in individuals with skin conditions has focused on individuals with psoriasis (Ginsburg and Link, 1989, 1993; Gupta *et al.* 1998), it was predicted in this study that individuals with eczema would face similar stigmatisation. However, the results indicate that there is a significant difference between the psoriasis and eczema groups on total scores on the experience of Skin Complaints measure. Non-significant results are reported on four of the measure sub-scales, self-esteem, retreat, rejection and concealment between the psoriasis and eczema groups. Consequently, the only factor that shows a significant difference between the psoriasis and eczema groups is composure. The differences in age of onset of skin disease and current age differences between the psoriasis and eczema groups could explain the significant differences on the total scores obtained. Perhaps early onset in eczema allows greater acceptance of means by which to cope with stigma associated with having a skin condition by the time an individual reaches adulthood. In addition, eczema is perhaps a less stigmatising condition, when it develops in childhood. As the National Eczema Society (1997) suggest that between 5 and 15 percent of children experience eczema, it is relatively common and in general has a higher profile than psoriasis. Another explanation maybe in relation to stress levels among individuals with a skin condition. Certainly, there has been greater interest in the role of stress in psoriasis, with suggestions that stress is a more significant feature of psoriasis, than it is of eczema. Perhaps the stress of stigmatisation is therefore greater in individuals with psoriasis than for those with

eczema. The factor on the EoSC measure, that shows a significant difference between the two groups, is composure. This factor reflects calmness and confidence in spite of having a skin disease. The results suggest that eczema participants show significantly more composure than psoriasis participants. Perhaps developing a skin condition at a younger age allows eczema patients to develop strategies for dealing with stigma. As psoriasis typically develops at a crucial developmental period, late adolescence and early adulthood, the individual with psoriasis may be more aware of stigmatisation and less able to deal with it. Gupta *et al.* (1989) noted that 58 percent of psoriasis patients develop their skin condition during this period of development, when we are most self-conscious of our appearance and the image we portray. Evidently this is only one suggestion and further investigation, perhaps comparing psoriasis and eczema subjects at this 'critical period', is required.

4.4.2 Hypothesis 7 – Stigma experience modulates coping.

As mentioned earlier, Ginsburg and Link (1993) suggested that further research examining stigmatisation should explore the coping strategies employed by individuals to deal with this. In the current study, this hypothesis was analysed by comparing total score on the Experience of Skin Complaints measure and 13 items on the COPE. Using a stepwise regression analysis, the results suggest that the only factor on the COPE which is predictive of total stigma score is behavioural disengagement. Behavioural disengagement, as defined by Carver *et al.* (1989), refers to the individual reducing their effort to deal with a stressful situation and in effect giving up. Theoretically, behavioural disengagement is most likely to occur when the individual expects poor coping outcomes. Carver *et al.* (1989) compare this

phenomenon to the literature on learned helplessness. This result perhaps suggests that individuals with a skin condition who experience stigma are most likely to cope with this stigmatisation by giving up in their attempts to effectively deal with the problem of stigmatisation. However, in individuals with chronic illness where active steps will not cure their condition, behavioural disengagement may actually be an effective way to deal with the difficulties associated with stigmatisation. Fortune *et al.* (1997a) suggest that individuals with diseases with an unpredictable course, as with psoriasis and eczema, display dominant avoidance strategies targeted at suppressing anxiety and depression associated with insecurities about the future. This would imply overlap with the factor relating to acceptance, which has not been found to be significant in this study. Despite this speculation, behavioural disengagement accounts for only a small percentage of the variance in relation to stigma experience and more detailed research is required to further establish the relationship between stigmatisation and coping styles.

Due to the limited number of participants in this study, a similar multiple regression analysis examining the relationship between stigma and coping in the psoriasis and eczema groups was not possible. To examine the relationship between stigma experience and coping for each group, Kendall's Tau correlations were conducted. The results suggest that there is not any major difference between the coping mechanisms used by each group in relation to stigma experience. Only one factor significantly correlates with stigma experience in the eczema group, alcohol and drugs. Although the factor of alcohol and drugs on the COPE was not initially validated, it is interesting that this should be associated with greater stigma

experience in individuals with eczema. There is certainly a lack of research comparing alcohol use in individuals with skin conditions, although anecdotal evidence suggests alcohol use is increased in psoriasis patients compared to other groups of individuals with chronic illness. Hughes *et al.*, (1983) suggested that alcohol is commonly abused by individuals as a means of controlling the pain and itching associated with having a skin condition. It could be speculated that the eczema patients in this study experience greater pain and itching associated with their skin disease. As it was suggested earlier, individuals using certain emotion-focused coping techniques are more likely to report greater stigma experience. As much of the coping research suggests that emotion-focused coping is maladaptive, the current results appear to support this proposition, in that emotion-focused coping (behavioural disengagement) relates to greater stigma experience. Further research is perhaps required to establish if some forms of emotion-focused coping are in fact adaptive for those individuals faced with the stresses that accompany having a chronic illness.

4.5 QUALITATIVE ANALYSIS

4.5.1 Discussion of Findings

The aim of the qualitative analysis in this study was to report the diversity of experiences with everyday problems and feelings of stigmatisation, endured by individuals with psoriasis and eczema. It was also hoped to explore the coping strategies used by individuals to deal with their chronic illness. As discussed further

in section 4.5.2, given the small numbers involved in this part of the current study, no claim is made that the opinions expressed statistically represent the experience of psoriasis and eczema patients in general. There have been very few studies using qualitative methods to explore the problems associated with having a chronic skin condition. Taylor and Buckwalter (1998), as an adjunct to a coping questionnaire, asked open-ended questions relating to how individuals with psoriasis coped with their skin condition. The specific themes identified in the Taylor and Buckwalter (1988), study and specific categories from the general coping literature, have been used to inform theme generation in the current study. Additional themes relating to the stigma experience have been based on the main research studies examining stigma experience in psoriasis patients (Ginsburg and Link, 1989, 1993; Gupta *et al.* 1989, 1998).

The first set of themes, identified from the transcripts, relate to stigma experience and stressful situations. Four main themes were identified; ignorance of others, situations relating to skin exposure, the messiness and expense of treatment regimes and the effects of stress on the course of the skin condition. Ignorance of other individuals and situations relating to exposure appear to be interrelated. The majority of the participants interviewed could mention at least one situation where they had been upset by the comments or looks from others about their skin condition. Fortune *et al.*, (1997b) commented that stress, resulting from anticipating other people's reactions to their psoriasis, contributed more to the variance in patients' disability in everyday life than any other medical or health status variable. These situations were not always overt, as with the situations described by Ginsburg and

Link (1989); Gupta *et al.*, (1998). Many referred to glances from strangers and unwanted questioning about their skin. As a consequence, several participants reported that they tended to cover-up the affected areas whenever possible. This appeared to be of greatest frustration on holiday, with many reporting that they felt uncomfortable wearing shorts and tee-shirts and would avoid this whenever possible. The shedding of skin is a particularly frustrating aspect of having a skin condition. Several participants indicated that they avoided wearing dark clothes and were conscious in the company of others to avoid sitting in chairs where any flakes of skin left behind would be noticed. Such issues are a constant reminder for individuals with psoriasis and eczema that they have a chronic skin condition. This is also reflected in the messiness of treatment. Several subjects commented on the problems associated with the greasy emollients used to control their condition. Other problems relate to the side effects of treatment. Those using steroid creams fear thinning of the skin in later life, while those receiving light treatment incur a higher risk of developing skin cancer. It appears that, on top of the daily stresses associated with having a skin condition, there is the added worry the treatments to control the condition may result in other problems later. In relation to the effect of stress on skin condition, surprisingly few participants indicated awareness that stress made their condition worse. This is interesting given the vast amount of literature exploring the role of stress in the onset and maintenance of both psoriasis and eczema. As Ginsburg and Link (1993) suggest that perhaps the individual is unaware of the subtle life stresses that can effect their skin condition.

The second category of themes relates to emotion-focused coping. Five themes, broadly relating to emotion-focused, were found. These relate to emotion-focused coping identified by Taylor and Buckwalter (1988) and Carver *et al.*, (1989). These are; avoidance, acceptance, minimisation, feeling lucky and seeking emotional support. Other coping strategies identified in the literature were not found in the participant's transcripts, such as venting of emotions (anger) or use of religion, alcohol or drugs. However, the themes identified are probably restricted by the types of questions asked in the semi-structured interviews. Avoidance and acceptance appear to be the main emotion-focused coping strategies used by this subject group. Clearly, there is some degree of overlap with the previous theme relating to situations where the skin is exposed with general avoidance. Avoidance of activities, such as swimming, appears to be common as a means of avoiding exposure and subsequent embarrassment. Two participants suggested that swimming pools should hold special evenings for sufferers of skin disease to avoid embarrassment and unwanted stares. Acceptance of having a skin condition, and coming to terms with it, is also a common coping strategy in this group. With the prospect of having a life-long condition with an unpredictable course, this is perhaps the most effective strategy for dealing with the problems associated with a chronic skin condition. Interestingly this was not reflected in the main study, comparing acceptance with psychosocial impairment. Acceptance appears to be linked with two other themes identified, minimisation and feeling lucky. Several individuals identified that they felt a fraud and did not really view themselves as ill and those who had never had lesions on their face felt very fortunate. Feeling a fraud was especially common among the hospitalised subjects, who found it difficult to justify a four-week stay in

hospital for “just a skin problem”. The fifth theme identified relates to seeking social support. Many of the participants appeared to feel isolated by their condition. The opportunity to speak to other sufferers or hospital staff, who “can understand what is the matter with you”, is greatly appreciated. It is possible that such day to day isolation in the community can contribute to disease-related stress.

In comparison to emotion-focused coping, problem-focused coping strategies were less frequently reported by the participants. Again, this may be related to the limited questions asked in the semi-structured interviews. Four themes were identified in relation to this category; seeking appropriate treatment, educating oneself about the skin condition, educating others and focusing on other activities. The most frequently reported coping method was seeking appropriate treatment, which corresponds to results reported in the Taylor and Buckwalter (1988) study. Most subjects recognised that, when they could no longer control their symptoms themselves, contacting their dermatologist was the most appropriate course of action. Others recognised the need to educate others about having a skin condition and taking positive action to change the misconceptions of others. The lack of problem-focused coping reflects the results found in the quantitative analysis and poses the question whether the term problem-focused or active coping is appropriate, when the stressor, the chronic skin condition, can not be removed.

Some of the issues discussed by participants in the interviews did not quite fit with the themes identified above. Consequently, an additional category was generated from the participants comments. The main themes identified were frustration at the

unpredictability of skin condition, self-esteem, the effect on significant others(family and friends) and positive cognitions(viewing their skin condition as positive). The most frequently reported of these themes was the frustration at the unpredictability of psoriasis and eczema. Although many of the treatments hold out great promise of a cure, in reality the majority of patients only receive a brief remission from their symptoms. One may speculate that this contributes to the high rates of depression reported to occur in individuals with skin complaints (Gupta and Gupta, 1998). In addition, this unpredictability may hamper the use of problem-focused coping, if the stressor is only going to reappear again. Comments in the transcripts, which relate to the theme of self-esteem, reflect the devastating effect a skin condition can have for some individuals. Participants referred to “withdrawing into themselves”, “being anti-social” and “feeling awful and embarrassed”. Such opinions link with the extensive literature discussed earlier, reporting increased psychosocial difficulties for individuals with psoriasis and eczema when compared to controls. Interestingly, the third theme exploring the effect on significant others is not something that is extensively reported in the literature. There is some research relating to the difficulties that families of children with severe eczema experience, but not about the effects of adults having a skin disease. Families of adults with skin disease may have to help with treatment regimes, will certainly be aware of the messiness of some treatment and, for those who need frequent hospital treatment, endure long periods time when their relative is in hospital. The final theme identified, positive cognitions, could perhaps be classed as an effective coping strategy. These participants emphasised the importance of being positive to help cope with their skin condition. One participant, who had been hospitalised for four months when

interviewed, commented that if he had not been positive he thought he would have been dead by now.

Clearly not all the comments made during the interviews could be categorised into the main themes given above. Those that have been identified demonstrate the extent to which both psoriasis and eczema can have a devastating effect on psychosocial wellbeing. Although many individuals with these skin conditions cope admirably with their disability, for others day-to-day coping is more difficult. Several authors have suggested the need for psychological therapy to enhance the sufferers sense of control over their skin condition and effectively manage the associated stresses, in particular stigmatisation (Taylor and Buckwalter, 1988; Ginsburg, 1996 and Metz & Jemec, 1996). Unfortunately as reviewed in the introduction, there has been limited development of psychological therapies for dermatology patients.

4.5.2 Methodological issues relating to qualitative analysis

Interpretation of qualitative data collected in this study is bounded by the fact that the analysis did not strictly adhere to any specific qualitative approach. The analysis was based around grounded theoretical methods as described by Henwood and Pidgeon (1995). In an attempt to link qualitative and quantitative paradigms, interpretation of the transcript information may have been compromised. This is particularly evident from the identification of themes from previous research rather than the themes being solely derived from the data. Despite the frequency with which the identified themes are reported by the participants, it is not implied that

these are representative of the total subject population. This analysis, although rich in the information it provides, is only pertinent to the particular subject group. However the use of a semi-structured interview, with open-ended questions, allowed for a diverse picture of individual experiences of having to live with a chronic skin condition, which are often missed in questionnaire methods. Obviously, the use of this format of interview imposes some constraints that could have been avoided by using depth interviewing, where the interviewee directs the structure of the interview. Analysis of the data was conducted by coding of the transcripts by the researcher. Coding of the transcripts could have been improved by the use of a more formal method of identifying themes, such as construct analysis. The analysis process could have been further enhanced by inter-rater reliability, with a second researcher re-coding the transcripts and minimising researcher bias. In addition, the transcripts tended to focus on individual experience, and the opportunity to find out about participants' opinions of their skin condition in general, may have further enriched the analysis.

Sample selection for this qualitative analysis was restricted by the time constraints of the research. Consequently, information may have been lost by only asking the first fifty participants if they wished to volunteer to take part in an interview. This was evident throughout the research period, as many of the participants in the main study supplemented the information provide by the questionnaire method. This was usually noted by comments attached to the questionnaires or directly approaching the researcher and offering to participate further in the research if required.

4.6 GENERAL METHODOLOGICAL ISSUES

Methodological issues relating to the qualitative analysis have already been discussed above. In relation to the general methodological issues, there are several points that warrant further discussion and have implications for the interpretation of the results. One of the main difficulties was the lack of a measure of skin severity. As discussed earlier, there is a lack of consensus over effective means of measuring severity of skin disease. In addition, the time constraints, and recruitment of participants at different points in their treatment, made measurement of severity in this study an impossible task. Many of the subjects who participated in the study were receiving light treatment and for many at the end of their treatment they were virtually clear of any skin lesions. Consequently, separating the subjects on the basis of the anatomical location of their skin conditions was potentially not the most reliable method of distinguishing between individuals. In reality, no individual indicated that they no longer had any skin lesions. Thus, they probably indicated the anatomical location in which their skin condition usually appears. Consequently, it may have been advantageous to record current method of treatment and stage in treatment as additional variables.

In the initial stages of this study, it was hoped to allow further comparisons between inpatients and outpatient with psoriasis and eczema. Unfortunately, the number of inpatients who participated in the study was minimal. In the early stages of data collection, a influenza epidemic limited the number of beds available for psoriasis and eczema patients in the dermatology ward. As much of the current literature

includes inpatients and outpatients within the same subject groups, the collapsing of the subject groups in this study was not expected to compromise results.

Power calculations suggested that 30 participants were required in both the psoriasis and eczema groups to produce a large effect size for the statistical analysis used. Larger numbers of individuals with psoriasis receive light therapy as a treatment method, than eczema sufferers. As patients who receive light therapy were the most accessible in recruitment of subjects, there is a wide variation in the number of subjects in each group, 39 in the psoriasis group and 25 in the eczema group. A larger and more equal sample size may have resulted in additional, more robust findings.

Another area of this study, that warrants further discussion, is the problem associated with the questionnaire methods used. Although the Experience of Skin Complaints measure claims to be equally applicable for use with all skin conditions, the authors only tested it on individuals with psoriasis. As reported earlier, the measure was adapted for use in this study, through modification of the scoring scale to include a neutral option. Although this is a possible improvement to the scoring, it limits the range of potential scores on each factor. As discussed earlier, one factor on the measure consists of only four items compared to six to nine items on other factors. With the addition of a neutral scoring option, this increases the potential for a floor effect in the reported results. Many of the participants indicated that they found the questions on this measure complicated. Consequently, there is a high probability that false positive responses have been obtained. They also commented on the repetitive

nature and excessive length of the COPE measure. Participants reported difficulties with the questions relating to the sub-scales for alcohol and drugs, religion and humour where there is very little variation in the four questions corresponding to each factor. Perhaps the difficulties in the comprehension and completion of these two measures restricted the number of participants who actually completed and returned the measures. In addition, the difficulties with these measures are evident in those participants who were excluded from this study, the majority for non-completion of the COPE or Experience of Skin Complaints measure.

4.7 FUTURE STUDIES

Suggestions for future studies in relation to the hypotheses outlined have been expanded on, where appropriate, throughout the discussion. Ideas for more extensive studies are discussed below.

Initially, it was hoped to compare the difference between inpatients and outpatients in relation to stigmatisation, quality of life and coping mechanisms. Previous research has tentatively suggested that hospitalised groups have lower anxiety and depression than outpatients (Hashiro and Okumura, 1997) and that those in hospital report feeling less stigmatised by their skin condition (Ginsburg and Link, 1993). Others have suggested that psychosocial problems are actually greater for the hospitalised patient (Polenghi *et al.*, 1994 and Mazzetti *et al.*, 1994). Restricted

subject numbers in the current study prevented such a comparison, but it is clear that further research is required to clarify these differences.

As mentioned earlier, many of the studies quantifying psychosocial impairment in individuals with psoriasis and eczema have suggested the need for psychological input to become standard in dermatological treatment. To date, research in this area has been limited and at times vague. Many of the participants who were interviewed and those who just completed the questionnaire methods welcomed the opportunity to discuss their difficulties and wished more was on offer to help them cope with the non-clinical aspects of their skin condition. The use of cognitive-behavioural techniques appear to be highly relevant to the problems discussed by the participants, yet only a handful of papers have been published using these techniques with dermatology patients. This is an obvious area where further research would be beneficial.

4.8 CONCLUSIONS

Psychological research in dermatology is still in its infancy. The response of the participants in this study was overwhelming, in terms of their enthusiasm to participate and their eagerness to discuss the difficulties they had faced as a consequence of their skin condition. The extent of psychosocial impairment and experience of stigma was greater than expected, very few reported that they had experienced no problems due to their skin condition. The results of this study

indicated that individuals with psoriasis and eczema have similar levels of psychosocial impairment, but psoriasis sufferers experience greater stigmatisation. Coping mechanisms do not appear to greatly influence stigma experience. In general, much of research has focused on quantifying the extent of psychosocial impairment and further work is needed to explore effective methods of helping psoriasis and eczema sufferers cope with these difficulties.

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APPENDIX 1 – MODIFIED EXPERIENCE OF SKIN COMPLAINTS MEASURE

QUESTIONNAIRE FOR THE EXPERIENCE OF SKIN

COMPLAINTS

Name

Date.....

We are interested in your everyday experiences of having a chronic skin condition. Below are a number of statements, which relate to having a skin condition.

Read each statement and circle the number which comes closest to how you feel about each item, using the response choice listed below.

Strongly Agree	Agree	Neither Agree or Disagree	Disagree	Strongly Disagree
1	2	3	4	5

1	I have told people close to me to keep the fact of my skin a secret	1 2 3 4 5
2	Many people assume that having a skin disease as I do is a sign of personal weakness.	1 2 3 4 5
3	I often think that others think that patients with a skin disease are 'dirty'.	1 2 3 4 5
4	I sometimes think that family members feel that I am weaker because I have a skin disease and they do not.	1 2 3 4 5
5	If I thought an employer would discriminate against someone because of a skin disease like mine, I would not apply for the job.	1 2 3 4 5
6	When my skin disease is severe, I am too ashamed to engage in sexual activity.	1 2 3 4 5
7	If my child developed such a skin disease too, I feel he or she could have as good a life as if he or she did not have it.	1 2 3 4 5
8	I do my best to keep family members I do not live with from hearing anything about my disease	1 2 3 4 5
9	I do not mind when a family member is disturbed by the consequences of my disease (e.g. scales, smell of medicines or scratching)	1 2 3 4 5
10	If my child were to have the same skin disease as I, I think that he or she could develop his or her potential just as though he or she did not have it.	1 2 3 4 5
11	I rarely feel the need to hide the fact that I have my skin disease.	1 2 3 4 5
12	When people learn that you have a skin disease like me, they begin to search for flaws in your personality	1 2 3 4 5

13	Patients with a skin disease are treated like lepers.	1	2	3	4	5
14	I feel physically unattractive and sexually undesirable when my skin is bad.	1	2	3	4	5
15	I never feel embarrassed or ashamed because of my skin disease.	1	2	3	4	5
16	If my child were to develop such a skin disease, I would not feel guilty	1	2	3	4	5
17	An employer who knows a person has a history of skin disease will probably pass over the application and give the job to someone else.	1	2	3	4	5
18	If I were to make a new friend, I would tell him or her all about my skin disease.	1	2	3	4	5
19	Some people act as though my having my skin disease were my fault somehow.	1	2	3	4	5
20	There are times when I feel 'dirty', as though there is something deeply the matter with me, beyond the fact of my skin disease.	1	2	3	4	5
21	People avoid me and shy away for fear that the skin rash is contagious.	1	2	3	4	5
22	Having to use many creams and medications on the skin keeps the patient with a skin disease preoccupied with feeling unclean.	1	2	3	4	5
23	If someone notices my sick skin and asks what it is I do not say that it is a skin disease.	1	2	3	4	5
24	I would not apply or get training for a job that involved dealing with the public because of my skin disease.	1	2	3	4	5
25	When my skin has broken out badly, there are times when I feel that life is not worth living.	1	2	3	4	5
26	I often feel totally alone with my skin disease.	1	2	3	4	5
27	I have that feeling that I am worth less than others	1	2	3	4	5
28	I sometimes think I am rejected or treated with caution by others because of my skin.	1	2	3	4	5
29	It is hard for me to admit that I have a skin disease.	1	2	3	4	5
30	I have thought of committing suicide because of my skin disease.	1	2	3	4	5
31	I try to dress in a manner that my skin disease is as unnoticeable as possible.	1	2	3	4	5
32	Questions concerning my skin disease are embarrassing for me	1	2	3	4	5
33	I do not go swimming or have a sauna because others could feel disgusted by my skin disease	1	2	3	4	5
34	I have the feeling that others stare at my skin symptoms	1	2	3	4	5

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QUESTIONNAIRE FOR THE EXPERIENCE OF SKIN COMPLAINTS

MODIFIED SCORING TO INCLUDE NEUTRAL MIDPOINT

	FACTORS	SCORING
1	<i>Self-esteem</i>	4 3 0 2 1
2	<i>Rejection</i>	4 3 0 2 1
3	<i>Rejection</i>	4 3 0 2 1
4	<i>Rejection</i>	4 3 0 2 1
5	<i>Retreat</i>	4 3 0 2 1
6	<i>Retreat</i>	4 3 0 2 1
7	<i>Composure</i>	1 2 0 3 4
8	<i>Concealment</i>	4 3 0 2 1
9	<i>Composure</i>	1 2 0 3 4
10	<i>Composure</i>	1 2 0 3 4
11	<i>Composure</i>	1 2 0 3 4
12	<i>Rejection</i>	4 3 0 2 1
13	<i>Rejection</i>	4 3 0 2 1
14	<i>Retreat</i>	4 3 0 2 1
15	<i>Composure</i>	1 2 0 3 4
16	<i>Composure</i>	1 2 0 3 4
17	<i>Retreat</i>	4 3 0 2 1
18	<i>Concealment</i>	1 2 0 3 4
19	<i>Rejection</i>	4 3 0 2 1
20	<i>Self-esteem</i>	4 3 0 2 1
21	<i>Rejection</i>	4 3 0 2 1
22	<i>Self-esteem</i>	4 3 0 2 1
23	<i>Rejection</i>	4 3 0 2 1
24	<i>Retreat</i>	4 3 0 2 1
25	<i>Self-esteem</i>	4 3 0 2 1
26	<i>Self-esteem</i>	4 3 0 2 1
27	<i>Self-esteem</i>	4 3 0 2 1
28	<i>Rejection</i>	4 3 0 2 1
29	<i>Concealment</i>	4 3 0 2 1
30	<i>Self-esteem</i>	4 3 0 2 1
31	<i>Retreat</i>	4 3 0 2 1
32	<i>Concealment</i>	4 3 0 2 1
33	<i>Retreat</i>	4 3 0 2 1
34	<i>Retreat</i>	4 3 0 2 1

APPENDIX 2 - COPE

Name:

Date: Record Number:

We are interested in how people respond when they confront difficulties in their lives, such as having a chronic skin condition. This questionnaire asks you to indicate what you generally do and feel about having a skin condition.

Think about how you deal with your skin condition. Then respond to each of the following items by choosing one number for each, using the response choices listed just below.

1 = I usually don't do this at all.

2 = I usually do this a little bit

3 = I usually do this a medium amount

4 = I usually do this a lot

Please answer every item. There are no 'right' or 'wrong' answers, so choose the most accurate answer for YOU – not what you think 'most people' would say or do.

1. I try to grow as a person as a result of the experience.
2. I turn to work or other substitute activities to take my mind off things.
3. I get upset and let my emotions out.
4. I try to get advice from someone about what to do.
5. I concentrate my efforts on doing something about it.
6. I say to myself "this isn't real".
7. I put my trust in God.
8. I laugh about the situation.
9. I admit to myself that I can't deal with it, and give up trying.
10. I restrain myself from doing anything too quickly.

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11. I discuss my feelings with someone.
12. I use alcohol or drugs to make myself feel better.
13. I get used to the idea that it happened.
14. I talk to someone to find out more about the situation.
15. I keep myself from getting distracted by other thoughts or activities.
16. I daydream about things other than this.
17. I get upset, and am really aware of it.
18. I seek God's help.
19. I make a plan of action.
20. I make jokes about it.

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PLEASE TURN OVER

21. I accept that this has happened and that it can't be changed.
22. I hold off doing anything about it until the situation permits.
23. I try to get emotional support from friends and relatives.
24. I just give up trying to reach my goal.
25. I take additional action to try to get rid of the problem.
26. I try to lose myself for a while by drinking alcohol or taking drugs.
27. I refuse to believe that it has happened.
28. I let my feelings out.
29. I try to see it in a different light, to make it seem more positive.
30. I talk to someone who could do something concrete about the problem.
31. I sleep more than usual.
32. I try to come up with a strategy about what to do.
33. I focus on dealing with this problem and, if necessary, let other things slide a little.
34. I get sympathy and understanding from someone.
35. I drink alcohol or take drugs, in order to think about it less.
36. I kid around about it.
37. I give up the attempt to get what I want.
38. I look for something good in what is happening.
39. I think about how I might best handle the problem.
40. I pretend that it hasn't really happened.
41. I make sure not to make matters worse by acting too soon.
42. I try hard to prevent other things from interfering with my efforts at dealing with this.
43. I go to the cinema or watch television, to think about it less.
44. I accept the reality of the fact that it happened.
45. I ask people who have had similar experiences what they did.
46. I feel a lot of emotional distress and I find myself expressing those feelings a lot.
47. I take direct action to get around the problem.
48. I try to find comfort in my religion.
49. I force myself to wait for the right time to do something.
50. I make fun of the situation.
51. I reduce the amount of effort I'm putting into solving the problem.
52. I talk to someone about how I feel.
53. I use alcohol or drugs to help me get through it.
54. I learn to live with it.
55. I put aside other activities in order to concentrate on this.
56. I think hard about what steps to take.
57. I act as though it hasn't even happened.
58. I do what has to be done, one step at a time.
59. I learn something from the experience.
60. I pray more than usual.

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APPENDIX 3 – DERMATOLOGY QUALITY OF LIFE SCALES

DERMATOLOGY QUALITY OF LIFE QUESTIONNAIRE

This scale consists of a number of words that describe different feelings and emotions. Please read each item and then mark the appropriate answer in the box to indicate to what extent you generally feel this way about your skin problem.

	very slightly or not at all	a little	moderately	quite a bit	extremely
feel embarrassed					
feel ashamed					
feel depressed					
worry about appearance					
feel distressed					
feel suicidal					
feel self conscious					
worry about what others think					
feel short tempered					
feel lack of hope					
feel isolated					
feel lack of understanding from others					
feel dependent					
worry about reactions of others					
feel anxious					
feel frustrated					
worry about long- term effects					

Please indicate how much your skin problem generally affects or restricts you
in these things

	very slightly or not at all	a little	moderately	quite a bit	extremely	not relevant
going out						
walking						
making friends/ meeting people						
choice of clothes						
summer activities/ swimming						
going out in the sun						
household tasks						
sleep						
work						
sexual activities						
bathing						
sporting activities/ exercise						

APPENDIX 4 – SUBJECT INSTRUCTION SHEETS

OUTPATIENT INSTRUCTION SHEET

Thank you for agreeing to take part in this study. Before completing the questionnaires it would be helpful if you could provide the following information.

NAME:

DATE OF BIRTH:

▪ DERMATOLOGY CONSULTANT:

▪ SKIN CONDITION (please tick):

ECZEMA

☐

PSORIASIS

☐

▪ HOW LONG HAVE YOU HAD THIS SKIN CONDITION (in years)?

▪ WHICH SITES ON YOUR BODY ARE MOST AFFECTED? (please tick)

a) Face / Head

☐

b) Hands / Wrists

☐

c) Chest / Abdomen / Back

☐

d) Arms / Legs and/or Feet

☐

e) All over

☐

- 1) Please complete the following three questionnaires. Ensure that you answer every question.
- 2) If you wish to participate further in this research please read the attached letter and return the completed form with your questionnaires.
- 3) Once you have completed the questionnaires please put them in the envelope with the information sheet and consent form.
- 4) Return either by post or place in the box provided at the outpatient department.

Thank you very much for your help.

INPATIENT INSTRUCTION SHEET

Thank you for agreeing to take part in this study. Before completing the questionnaires it would be helpful if you could provide the following information.

NAME:

DATE OF BIRTH:

▪ DERMATOLOGY CONSULTANT:

▪ SKIN CONDITION (please tick):

ECZEMA ☐ PSORIASIS ☐

▪ HOW LONG HAVE YOU HAD THIS SKIN CONDITION (in years)?

▪ WHICH SITES ON YOUR BODY ARE MOST AFFECTED? (please tick)

- | | |
|----------------------------|--------------------------|
| a) Face / Head | <input type="checkbox"/> |
| b) Hands / Wrists | <input type="checkbox"/> |
| c) Chest / Abdomen / Back | <input type="checkbox"/> |
| d) Arms / Legs and/or Feet | <input type="checkbox"/> |
| e) All over | <input type="checkbox"/> |

- 1) Please complete the following three questionnaires. Ensure that you answer every question.
- 2) If you wish to participate further in this research please read the attached letter and return the completed form with your questionnaires.
- 3) Once you have completed the questionnaires please put them in the envelope with this sheet and the consent form.
- 4) Return to the researcher or ward staff.

Thank you very much for your help.

APPENDIX 5 – SEMI-STRUCTURED INTERVIEW OUTLINE

Semi-Structured Interview

Identifier

Background Information

Type of Skin Condition

Length of time since onset

Treatment

Coping

What do you find most frustrating about having eczema / psoriasis?

What sort of things / situations make your eczema / psoriasis worse?

What do you find most useful in helping you deal with your skin condition?

Stigma Experience

Have you ever experienced a situation where someone has made a conscious effort not to touch you because of your skin condition?

If so, what?

How did that make you feel?

How did you respond?

Any Particular Issues Participants Wish to Raise About Their Responses to the Questionnaires

APPENDIX 6 – PARTICIPANT INFORMATION SHEET

PARTICIPANT INFORMATION SHEET

We invite you to participate in a research project. We believe it to be of potential importance. However, before you decide whether or not to participate, we need to be sure that you understand firstly why we are doing it, and secondly what would be involved if you agreed. We are therefore providing you with the following information. Read it carefully and be sure to ask any questions you have, and, if you want, discuss it with outsiders. We will do our best to explain and to provide any further information you may ask for now or later. You do not have to make an immediate decision.

1. The aim of this project is to find out about the problems you have to face as someone with eczema or psoriasis and how you are coping with this.
2. If you agree to take part, you will be asked to complete a few questionnaires. This will take around 20 minutes.
3. These can either be completed during your visit to the outpatient department or stay in the Dermatology ward. Alternatively you can take these home and return them in the reply-paid envelope provided.
4. If you wish to participate further in this study and are willing to attend for a short interview please complete the attached form and return with your questionnaires.
5. Anything you say will be treated in confidence and only the researchers will have access to the information provided.

Participation in this study is entirely voluntary and you are free to refuse to take part or to withdraw from the study at any time without having to give a reason and without this affecting your future medical care or your relationship with medical staff looking after you.

*The ***** Committee on Medical Research Ethics that has responsibility for scrutinising all proposals for medical research on humans in ***** has examined the proposal and has raised no objections from the point of view of medical ethics. (Research records may be examined by monitors from the Tayside Committee on Medical Research Ethics.)*

If you have any questions more information can be obtained from Lucy Kelman at the Clinical Psychology Department, ***** Hospital

APPENDIX 7 – LETTER TO ATTEND INTERVIEW

Clinical Psychology Department

Dear Patient

You have already been kind enough to complete questionnaires in connection with the study looking at the problems people with skin diseases have. In addition to the questionnaires we are interested in your own personal experiences of the problems you have had to face as a result of your skin disease, and in looking at the different ways eczema and psoriasis sufferers cope with this.

We are asking people who have completed the questionnaires if they would like to participate further in this study by attending an appointment at ***** Hospital (or your own home if this is more convenient). This would be a one-off appointment and would last approximately 45 minutes. We would hope to arrange this interview within the next three weeks. Unfortunately, we would be unable to reimburse you for any travel expenses.

If you are able to help us by attending, please complete the form below and return this with your questionnaires. If you would like any further information please contact Lucy Kelman.....

Thank you very much.

✂

Name:

Address:

Telephone No.:

Best day / time for appointment: (please tick)

	Tuesday	Wednesday	Thursday	Friday	Any Day
a.m.					
p.m.					

Any days that are not suitable within the next three weeks: